

1-1-2013

# National Survey of Stroke Survivors: Documenting the Experiences and Levels of Self-Reported Long-Term Need in Stroke Survivors in the First 5 years. Systematic Review: Factors Associated with Community Re-integration in the First 12 months Post Stroke: A Qualitative Synthesis.

Mary Walsh

*Royal College of Surgeons in Ireland*

Rose Galvin

*Royal College of Surgeons in Ireland, [rosegalvin@rcsi.ie](mailto:rosegalvin@rcsi.ie)*

Chris Macey

*Royal College of Surgeons in Ireland*

Cliona McCormack

*Royal College of Surgeons in Ireland*

Frances Horgan

*Royal College of Surgeons in Ireland, [fhorgan@rcsi.ie](mailto:fhorgan@rcsi.ie)*

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## Citation

Walsh M, Galvin R, Macey C, McCormack C, Horgan F. National Survey of Stroke Survivors: Documenting the Experiences and Levels of Self-Reported Long-Term Need in Stroke Survivors in the First 5 years. Systematic Review: Factors Associated with Community Re-integration in the First 12 months Post Stroke: A Qualitative Synthesis. Dublin: Royal College of Surgeons in Ireland, 2013.

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**School of Physiotherapy  
Royal College of Surgeons in Ireland**

**National Survey of Stroke Survivors:**  
Documenting the Experiences and Levels of Self-  
Reported Long-Term Need in Stroke Survivors in the  
First 5 years

**Systematic Review:**  
Factors Associated with Community Re-integration in  
the First 12 months Post Stroke: A Qualitative Synthesis

**Authors:** Walsh M, Galvin R, Macey C, McCormack C,  
Horgan F.

## Acknowledgements

This piece of research was funded through the National Disability Authority's Research Promotion Scheme 2013. It should be noted that the views expressed in the report do not necessarily reflect those of the National Disability Authority.

The Research Team wish to acknowledge the support and assistance of the following individuals:

Irish Heart Foundation, National Stroke Support Group Network.

In particular, the group co-ordinators who acted as gate-keepers for participants:

Ms Patricia Daly, Ms Mary J Foley, Ms Mary McCormack, Ms Mary Tobin, Ms Anne Marie Walsh, Mr Kevin Butterly, Ms Breda Jones, Ms Niamh Barrett, Ms Gemma Dunn, Ms Barbara Ginley, Ms Dolores McElligott, Mr Michael Mulvaney, Ms Eleanor Meally, Ms Isibéal Mc Coy, Ms Mary Diskin.

The Volunteer Stroke Scheme co-ordinators Ms Bridie Lyons and Ms Ina Murphy.

Ms Emma-Jane Morrissey from the Irish Heart Foundation Advocacy Team for her assistance in facilitating contact with the National Stroke Support Group Network and for promoting the survey online.

Headway Ireland, in particular Ms Liz Owens, Mr Richard Stables and individual group co-ordinators for promoting the survey online and with their group members.

Brí, Independent brain injury support and advocacy, in particular Mr Ned Rispin, Mr Paul Barrett, Ms Sandy Roper, Ms Geraldine Mooney and Mr Michael Downey for facilitating access to members in areas not serviced by Stroke Support Groups.

Ms Hannah Murugan, Clinical Nurse Specialist (CNS), St Luke's Hospital Kilkenny, Ms Christine McLaughlin, CNS Letterkenny General Hospital, Mr Jamie Sheehy, Community Physiotherapist, North Cork Lee, Ms Rachel Doherty, Community Speech and Language Therapist, New Ross, Ms Suzanne O'Callaghan, Senior Physiotherapist, Cavan General Hospital and Ms Sarah Durkan, Physiotherapist, Baggot Street Community Hospital for distributing surveys to eligible patients.

Ms Nicola Cogan, Tallaght hospital and Ms Irene Hartigan, School of Nursing and Midwifery, UCC for advertising the survey at stroke clinics.

Ms Aisling Creed, Senior Speech and Language Therapist, Baggot Street Community Hospital who provided advice in relation to the inclusion of stroke survivors with aphasia.

We acknowledge the assistance of Dr Christopher McKeivitt of King's College London for allowing us the use of the UK Stroke Survivor Needs Survey.

The Stroke Association UK for provision of recent UK stroke surveys.

The Project Steering Group members, Professor David Williams (RCSI), Professor Anne Hickey (RCSI), Professor Hannah McGee (RCSI) and Ms Aisling Creed.

We particularly thank the stroke survivors who participated in the pilot study, allowing us to ensure that the survey would be applicable in the Irish setting.

This project would not have been possible without the participation of over 200 stroke survivors who attended stroke support group meetings, completed the survey online or posted surveys to the research team. We would like to express gratitude to them for taking the time to share their stories.

We hope that the combined efforts of our contributors, sponsors and research team will motivate and inform improvements in community services for persons after stroke in Ireland.

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## **Executive Summary**

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### **Introduction**

In Ireland it is estimated that there are 30,000 persons living with residual effects of stroke.<sup>1</sup> The Irish National Audit of Stroke Care, carried out in 2007, identified substantial deficits in a number of areas including discharge planning, rehabilitation, on-going secondary prevention, and communication with patients and families.<sup>2</sup> The present study builds on the findings of the audit. It explores in detail the current needs of people post stroke in Ireland who are living in the community. It also provides a profile of many possible problems that stroke can cause. In addition it provides a comprehensive review of the literature.

### **Aim**

This report contains two distinct pieces of research:

- Firstly, a systematic review and qualitative synthesis (metasynthesis) of the literature was conducted. The aim of the systematic review was to identify perceived barriers and facilitators to community re-integration in the first 12 months after stroke, from the perspective of persons with stroke
- Secondly, a national survey of stroke survivors who experienced their stroke up to 5 years previously was carried out. The aim of the survey was to document the experiences and levels of self-reported long-term need among community-dwelling stroke survivors in Ireland

### **Methods of the National Survey**

Stroke survivors were recruited to take part in the survey primarily through the Irish Heart Foundation National Stroke Support Group Network and non-statutory organisations that provide support after acquired brain injury. The survey was also advertised online to a broader stroke population.

A questionnaire was developed to assess respondents' own perceptions of their recovery, community re-integration and on-going needs from existing validated questionnaires with the permission of the original authors.<sup>3</sup> Data collection took place between June and October 2013.

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<sup>1</sup> Irish Heart Foundation

<sup>2</sup> Horgan, et al., 2008

<sup>3</sup>McKevitt, et al., 2010, The Stroke Association, 2012



## **Main findings:**

### ***Systematic Review***

Eighteen articles, using qualitative methodology, were included in the final review. Four primary themes that were perceived to act as barriers or facilitators to community re-integration for individuals in the first year after stroke were identified from the included studies:

- Primary effects of stroke
- Personal factors
- Social factors
- Relationships with professionals

### ***National Survey***

- A total of 196 stroke survivors, aged between 24 and 89 years, responded to the survey
- Mobility difficulties were reported by eighty-three per cent of respondents. Emotional problems, fatigue, concentration and arm dysfunction were reported almost as commonly
- Of the 150 individuals with emotional difficulties only eleven per cent received psychological services
- Sixty per cent of respondents felt that their household finances were affected by their stroke. Thirty-six per cent of respondents reported paying privately for rehabilitation. Thirty-four per cent of respondents had to pay privately to adapt their home
- Over half of respondents needed help with personal care and two thirds needed help with household tasks since their stroke. Family provided most of this help
- Forty-two per cent of respondents who were in a relationship at the time of the survey felt that it has been significantly affected by their stroke
- Less than a quarter of respondents under the age of 66 have worked in a full or part-time capacity since their stroke, while sixty per cent of drivers have returned to driving

## **Conclusions**

Stroke had a personal, social and economical impact on the lives of many respondents. Successful return to work levels after stroke, as reported, were particularly low. Emotional distress and fatigue were common and were barriers to many activities. Satisfaction with the level of help available for these problems was poor.

## I. Introduction

### Context of Research

Stroke is a major cause of death and acquired disability in all societies in which it has been studied. Approximately 16 million first-ever strokes occur in the world annually, causing a total of 5.7 million deaths.<sup>4</sup> The true impact of stroke should be considered not only in terms of incidence and mortality rates, but also of disability. This often persists for a long time, sometimes permanently after stroke.<sup>5</sup> Each stroke is unique, but there are a number of common ways in which stroke can affect someone. Survivors can experience physical disability, or difficulties in processing language, in reading, in articulating, or in swallowing. They may also experience psychological problems such as anxiety and depression.<sup>6</sup>

Advances in acute stroke management and rehabilitation have improved survival rates and up to 80% of patients are discharged from the hospital setting to community care.<sup>7</sup> While these outcomes highlight the efficacy of stroke care pathways, stroke survivors frequently report dissatisfaction with re-integration into their community.<sup>8</sup>

### Stroke in Ireland

In Ireland it is estimated that there are 30,000 persons living with residual deficits after stroke.<sup>9</sup> Although many of them return to live in the community, some require nursing home care. This care accounts for the largest proportion of the total annual cost of stroke in Ireland, which is estimated to be between €489 and €805 million.<sup>10</sup> In contrast, current expenditure levels on community rehabilitation services are lower than they should be.<sup>10</sup>

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<sup>4</sup> Di Carlo, 2009

<sup>5</sup> Norrving and Kissela, 2013

<sup>6</sup> McKevitt, et al., 2011

<sup>7</sup> Forster, et al., 2012

<sup>8</sup> Wood, et al., 2010, Pang, et al., 2007

<sup>9</sup> Irish Heart Foundation

<sup>10</sup> Smith, et al., 2010

The first comprehensive National Audit of Stroke Care in the community and hospitals in the Republic of Ireland was conducted during 2006-2008.<sup>11</sup> The audit identified substantial deficits in a number of areas including primary prevention, emergency treatment in hospital, discharge planning, rehabilitation, on-going secondary prevention, and communication with patients and families. There was a lack of coordination and communication between the acute and community services, with a dearth of therapy services in both home and nursing home settings.

The National Cardiovascular Health Policy 2010 – 2019 report was published in May 2010. It acknowledged that little is known about the profile of stroke patients in the community. It suggested that rehabilitation should involve a continuing assessment of patient and carer needs and should promote a return to independent living and full participation in society. To facilitate community re-integration, it also recommended that a partnership framework should be developed between the Health Service Executive (HSE) and the voluntary sector to enable expansion of stroke rehabilitation support services.<sup>12</sup>

This report is designed to elucidate details about what is needed by people living in the community after stroke, to enable their continued recovery and successful re-integration into community life. These needs are presented from the viewpoint of stroke survivors themselves. This report is designed to be of benefit to policy makers, health care professionals in both inpatient and community settings and individuals living with the consequences of stroke.

## **Background**

This report contains two distinct pieces of research:

- Firstly a systematic review and qualitative meta-synthesis of the literature was conducted. The aim of the systematic review was to identify perceived barriers and facilitators to community re-integration in the first 12 months after stroke
- Secondly a national survey of stroke survivors who experienced their stroke up to 5 years previously was carried out. The aim of the survey was to document the experiences and levels of self-reported long-term need among community-dwelling stroke survivors in Ireland

## **Community Re-integration**

Community re-integration refers to 'being part of the mainstream of family and community life, discharging normal roles and responsibilities, and being an active and contributing member of one's social groups and of society as a

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<sup>11</sup> Horgan, et al., 2008

<sup>12</sup> Department of Health and Children, 2010

whole'.<sup>13</sup> In the context of stroke, the transition from the acute setting to the community remains a challenge. At this time, the person with stroke is required to assume increased responsibility for independent functioning in the absence of the supportive environment of the inpatient setting, with the family or other caregivers providing necessary assistance with activities of daily living.<sup>14</sup>

Evidence to date indicates that patient priorities for community re-integration after stroke differ from those of health care providers.<sup>15</sup> The majority of primary research has focused on a single or a few aspects of community re-integration after stroke such as physical, mental or functional impairments, social and leisure activities or family interactions. This is particularly evident in rehabilitation research focusing on the effects of interventions that aim to have an impact on a specific area of activity limitation or social participation, rather than all aspects of community re-integration. In contrast, stroke survivors tend to focus on the social aspects of recovery, including 'normality', re-establishing former identity and resuming previous occupational, family, social and recreational roles.<sup>15</sup> Therefore it is not surprising that many individuals with stroke and their carers experience depression, social isolation and reduced quality of life.<sup>16</sup> In addition the trajectory of recovery, in terms of matching physical and social demands, and the changing needs of the person with stroke during the process of community re-integration is not well understood. As such, there is a need to systematically review the barriers and facilitators to community re-integration experienced by people with stroke, in order to more adequately address the process of community re-integration after stroke.

### ***Brief Methodology of Systematic Review***

The systematic review of the literature in this report examines factors related to community re-integration in the first year after stroke from the perspective of people with stroke, through the process of meta-synthesis. Please see Appendix I for a detailed background of the methodology, complete search string and details of thematic analysis. The meta-synthesis comprised three steps:

1. Identifying relevant papers for inclusion
2. Critical appraisal and data extraction
3. Analysis and synthesis of findings

A systematic literature search was conducted in July 2013 and included the following search engines: PubMed, EMBASE, Cochrane Library, PsychInfo

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<sup>13</sup> Dijkers, 1998

<sup>14</sup> Bhogal, et al., 2003

<sup>15</sup> Wood, et al., 2010

<sup>16</sup> Cott, et al., 2007

EBSCO, CINAHL and SCOPUS. A combination of the following keywords and MeSH terms were used: "stroke" OR "cerebrovascular disorders" OR "haemorrhage" AND "re-integration" OR "reengagement" OR "engagement" OR "integration" OR "participation".

Papers were considered for inclusion only if they reported the use of established qualitative methods to explore factors associated with community re-integration in the first 12 months after stroke, from the perspective of individuals with stroke. Two reviewers (RG and MW) independently examined full-texts of eligible articles. We assessed the methodological quality of included papers using criteria based on the ten questions derived by the Critical Appraisal Skills Programme (CASP).<sup>17</sup> Thematic analysis was performed and recurrent themes summarised and presented.

### **Self-reported Long Term Need**

There is a growing body of international research evaluating self-reported need among community-dwelling stroke survivors through cross-sectional surveys. The Stroke Association UK Stroke Survivor Needs Survey was carried out in 2009. A total of 571 individuals, patients of randomly selected GP practices in England, Scotland, Wales and Northern Ireland, reported their needs in relation to problems experienced after stroke, everyday living, relationships, work, leisure, finances and information.<sup>18</sup> The National Stroke Foundation in Australia carried out a similar survey in 2007. Results from 104 stroke survivors and 76 carers, recruited via multiple sources, were published as the "Walk in Our Shoes" report. It summarises stroke survivors' experiences of the impact of stroke, support needed and access to services in the community.<sup>19</sup>

As part of the Irish National Audit of Stroke Care a national survey of stroke patients living in the community and their carers was carried out in 2007. A randomised stratified sample of 139 respondents between 6 months and 3 years post stroke took part. The survey primarily focused on satisfaction with inpatient care and discharge planning. It also explored the availability of community services and return to employment and driving. It demonstrated major deficits in the provision of information, support and services to people with stroke and their carers living in the community.<sup>20</sup>

The present study builds on the findings of the audit. It explores in detail the current needs of people living in the community post stroke and provides a profile of many possible problems that stroke can cause. It identifies gaps in health service provision, which could help to inform priorities for service

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<sup>17</sup> Critical Appraisal Skills Programme, 2011

<sup>18</sup> McKevitt, et al., 2010

<sup>19</sup> National Stroke Foundation, 2007

<sup>20</sup> Hickey, et al., 2008

development. In addition it explores several aspects of community re-integration.

The aim of the National Survey, presented in Chapter 3 of this report, was to document the experiences and levels of self-reported long-term need among persons up to 5 years post stroke. The objectives of the study were to:

- Describe individuals' experiences of services after their stroke
- Describe the support that they received following discharge from hospital after their stroke
- Describe the daily challenges that people face after experiencing a stroke
- Describe progress after stroke and perceived on-going needs
- Establish the personal impact of stroke on their daily lives
- Establish the financial impact of stroke on their daily lives

### ***Brief Methodology of National Stroke Survivor Survey***

Survey participants were primarily recruited through the Irish Heart Foundation National Stroke Support Group Network. Additional participants were recruited through two national non-statutory organisations: Headway Ireland and Brí, Independent brain injury support and advocacy. In all cases the coordinators of the groups acted as gatekeepers. In regions that do not have an active stroke support group the Clinical Nurse Specialist for Stroke, and other community health care professionals, invited eligible individuals to participate. The survey was also advertised online through the Irish Heart Foundation Stroke website ([www.stroke.ie](http://www.stroke.ie)), the Headway Ireland website ([www.headway.ie](http://www.headway.ie)), and social networking sites of both organisations. Volunteers were invited to participate if they:

- Were over 18 years of age
- Had a stroke up to 5 years ago
- Were able to give informed consent
- Were able to communicate with or without assistance
- Were living in their own home within the community
- Did not have significant cognitive impairment<sup>21</sup>

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<sup>21</sup> Significant cognitive impairment = An Abbreviated Mental Test Score of >6 (Hodkinson, 1972)

A questionnaire was developed to assess respondents' own perceptions of their recovery, community integration and on-going needs. It was developed from existing validated questionnaires with the permission of the original authors: The UK Stroke Survivor Needs Survey<sup>22</sup> and The Daily Life Survey.<sup>23</sup> The survey was piloted in June 2013 and adaptations were made based on the feedback given by stroke survivors. Please see Appendix 3 for the complete survey instrument. The questionnaire covered the following domains:

- Information about stroke
- Health after stroke
- Everyday living
- Work and leisure
- Family, friends and use of support groups
- Personal and household finances
- Other needs
- Facilitators of recovery

Each group coordinator identified eligible members and informed them about the study. The researchers (MW, FH and RG) then visited meetings at the convenience of the group. The purpose and procedure of the study was explained fully to all potential participants and informed consent was obtained. Participants were given the option of completing the survey face-to-face with a researcher, completing the survey independently and returning it by post, or completing the survey online. Detailed information was also provided and written/ explicit consent obtained from all participants who accessed the survey via the online portal or by post.

Ethical approval for the study was granted by the Royal College of Surgeons in Ireland's Research Ethics Committee. In addition, ethical approval was obtained from the Naas General Hospital Research Ethics Committee in order to access participants in their jurisdiction. Please see Appendix 2 for a more detailed methodology of the National Stroke Survivor Survey.

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<sup>22</sup> McKeivitt, et al., 2010

<sup>23</sup> The Stroke Association, 2012

## **2. Systematic Review: Factors Associated With Community Re-Integration In The First Year After Stroke**

### **2.1 Description of Studies**

#### **Identifying published papers relevant to the focus of the study**

The initial search string yielded 4,865 articles, of which 4,809 were excluded based on title and abstract. Figure 2.1.1 describes the flow of studies in the review. Two reviewers independently assessed the remaining 56 articles. Forty-three were subsequently excluded as they examined factors associated with community re-integration in participants with chronic stroke (>1 year) or the focus of the research question was not relevant to the topic of the present study. The reference lists of the 13 remaining articles were searched and five subsequent studies were included.<sup>24</sup> Therefore 18 articles were included in the final review.<sup>25</sup>

#### **Descriptive characteristics of the studies included**

The details of these studies are presented in Table 2.1.1. Studies included between 5 and 125 participants (median 14 participants) with a total number of 384 participants included across all studies. Participants' ages ranged between 29 and 94 years. The methodology used to describe participants' experiences of community re-integration after stroke varied across studies. The majority of studies employed a grounded theory methodology.<sup>26</sup> Other methodologies employed included "Phenomenology"<sup>27</sup> "naturalistic methodology",<sup>28</sup> "framework analysis",<sup>29</sup> "constant comparative method",<sup>30</sup> and "computer assisted thematic analysis".<sup>31</sup> These methodologies are appropriate and widely-used in qualitative research of this kind. For an explanation of these methodologies please see the glossary (Appendix 4). Two studies of mixed-methodology were included as the qualitative results were

<sup>24</sup> Carlsson, et al., 2009, Alaszewski, et al., 2007, Robison, et al., 2009, Jones, et al., 2008, Ellis-Hill, et al., 2009

<sup>25</sup> Erikson, et al., 2010b, Erikson, et al., 2010a, Burton, 2000, Jones, et al., 2008, Robison, et al., 2009, Gustafsson and Bootle, 2013, Ellis-Hill, et al., 2009, White, et al., 2012b, White, et al., 2012a, Rittman, et al., 2007, Dickson, et al., 2008, Kubina, et al., 2013, Carlsson, et al., 2009, O'Sullivan and Chard, 2010, Alaszewski, et al., 2007, Wood, et al., 2010, Barnsley, et al., 2012, Rochette, et al., 2007

<sup>26</sup> Wood, et al., 2010, Barnsley, et al., 2012, Burton, 2000, Erikson, et al., 2010a, Kubina, et al., 2013, White, et al., 2012a, White, et al., 2012b, Carlsson, et al., 2009

<sup>27</sup> Burton, 2000, Jones, et al., 2008, O'Sullivan and Chard, 2010, Rochette, et al., 2007

<sup>28</sup> Alaszewski, et al., 2007

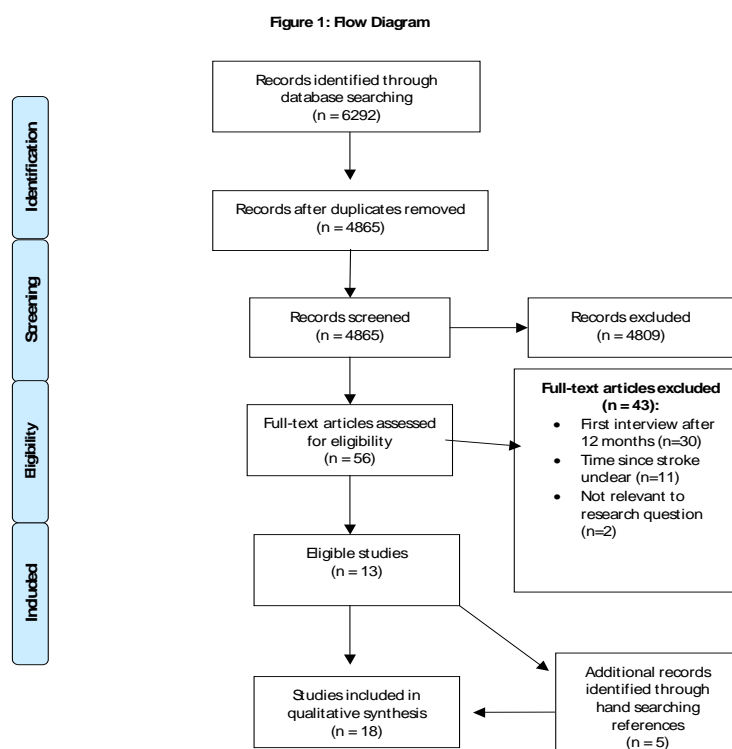
<sup>29</sup> Ellis-Hill, et al., 2009, Robison, et al., 2009

<sup>30</sup> Dickson, et al., 2008

<sup>31</sup> Rittman, et al., 2007



presented independently.<sup>32</sup> Six studies carried out interviews at a single time point in the community.<sup>33</sup> Time since stroke among participants in these six studies ranged from 3 weeks to 34 months, with all studies interviewing more than 80% of their participants before 12 months. The remaining 12 studies followed participants longitudinally for between 1 and 24 months post stroke.<sup>34</sup> Initial interviews of participants in these 12 studies were carried out between admission to hospital and 6 months post stroke.



**Figure 2.1.1: Flow diagram of studies included in the review**

<sup>32</sup> Rittman, et al., 2007, Rochette, et al., 2007

<sup>33</sup> Carlsson, et al., 2009, Dickson, et al., 2008, Ellis-Hill, et al., 2009, Jones, et al., 2008, O'Sullivan and Chard, 2010, Rittman, et al., 2007

<sup>34</sup> Alaszewski, et al., 2007, Barnsley, et al., 2012, Burton, 2000, Erikson, et al., 2010a, Erikson, et al., 2010b, Gustafsson and Bootle, 2013, Kubina, et al., 2013, Robison, et al., 2009, Rochette, et al., 2007, White, et al., 2012b, White, et al., 2012a, Wood, et al., 2010

**Table 2.1.1: Descriptive characteristics of studies included in the review**

	<b>Author(s)</b>	<b>Participant description (n, sex, age)</b>	<b>Time since stroke at 1<sup>st</sup> interview</b>	<b>Other interviews</b>	<b>Country</b>	<b>Qualitative methodology</b>
1	Alaszewski, et al., 2007	N=43 M=28 F=15 Age 30-59	< 3months	Every 5 months up to 18 months post stroke	England	Naturalistic methodologies
2	Barnsley et al., 2012	N= 19 M=12 F=7 Age 68.6±11.7*	Median 58 days (IQR 49-111)	3 months later	Australia	Grounded theory
3	Burton et al., 2000	N= 6 M=2 F=4 Age 52-81	Following initial admission	Every month for 12 months post stroke	England	Phenomenology Grounded theory
4	Carlsson et al., 2009	N=18 M=11 F=7 Age 30-69	12 months	None	Sweden	Grounded theory
5	Dickson et al., 2008	N= 24 M=15 F=9 Age 34-86	2-34 months (12.5% >12 months)	None	Scotland	Constant comparative method
6	Ellis-Hill et al., 2009	N= 20 M=12 F=8 Age 53-85	3-20 weeks	None	England	Framework analysis
7	Erikson et al., 2010a	N=9 M=6 F=3 Age 42-61	< 1 month	1, 3, 6, 9 and 12 months post stroke	Sweden	Grounded theory
8	Erikson et al., 2010b	N=7 M=4 F=3 Age 42-61	< 1month	1, 3, 6, and 12 months post stroke	Sweden	Grounded theory
9	Gustafsson and Bootle 2013	N=5 M=1 F=4 Age 36-79	23-93 days	1 month later	Australia	Inductive thematic analysis
10	Jones et al., 2008	N=10 M=6 F=4 Age 29-75	6 weeks-13 months	None	England	Phenomenology
11	Kubina et al., 2013	N=6 M=3 F=3 Age 40-68	6 months	6,9,12,18 and 24 months post stroke	Canada	Constructivist paradigm Grounded theory
12	O'Sullivan and Chard 2010	N=5 M=3 F=2 Age 68-84	< 1 year	None	Ireland	Phenomenology

	<b>Author(s)</b>	<b>Participant description (n, sex, age)</b>	<b>Time since stroke at 1<sup>st</sup> interview</b>	<b>Other interviews</b>	<b>Country</b>	<b>Qualitative methodology</b>
13	Rittman et al., 2007	N=125 M=123 F=2 Age 40-93	1-6 months	None	USA	Mixed methods: computer assisted thematic analysis for qualitative component
14	Robison et al., 2009	N=19 M=11 F=8 Age 53-85	7-39 days post discharge (median 16 days)	12 months post stroke	England	Framework analysis
15	Rochette et al., 2007	N=5 M=1 F=4 Age 61-83	3-4 weeks	3 and 6 months post stroke	Canada	Mixed methods: qualitative component based on phenomenology
16	White et al., 2012a	N=31 M=17 F=14 Age 37-94	"At baseline" for 23 participants. Unclear when cross-sectional took place	3, 6, 9 and 12 months with 23 participants. Single interview with 8 participants	Australia	Iterative methodology Analysis: An inductive thematic approach using modified grounded theory
17	White et al., 2012b	N=22 M=10 F=12 Age 50-94	"At baseline" for 16. Unclear when cross-sectional took place	3, 6, 9 and 12 months with 16 participants. Single interview with 6 participants	Australia	Iterative methodology Analysis: An inductive thematic approach using modified grounded theory
18	Wood et al., 2010	N=10 M=6 F=4 Age 31-79	Pre-discharge	2 weeks, 3, 6 and 12 months post stroke	Canada	Symbolic interactionism Grounded theory-inductive approach
Age reported as mean $\pm$ standard deviation IQR= Interquartile range						

## Quality appraisal of the studies

Included studies were assessed for rigour and methodological quality in order to assess the credibility of their findings. Overall studies were found to be of good methodological quality as assessed using the Critical Appraisal Skills Programme (CASP) criteria.<sup>35</sup> A summary of CASP questions evaluated for each study is presented in Table 2.1.2. Please see Appendix I for further clarification of quality assessment findings. In general, clear descriptions of data collection, analysis and results were provided with sufficient evidence presented to support conclusions. Implications for practice and recommendations for further research were also presented well.

A number of methodological limitations were noted across studies. Several authors failed to provide sufficient explanation as to why some individuals refused to take part, leaving the reader unable to assess for selection bias. Three studies did report the number of individuals who refused,<sup>36</sup> one study reported there were no refusals<sup>37</sup> while two studies acknowledged that no information was available on those who chose not to take part<sup>38</sup>. Data saturation was not discussed in nine studies<sup>39</sup> and was not achieved in one study.<sup>40</sup>

Of the eighteen papers under review only three demonstrated evidence that the relationship between the researcher and the participants was adequately considered. Two of these studies discussed that the researcher had no previous relationship with the participants<sup>41</sup> and the third acknowledged that the two authors' experience as occupational therapists in stroke rehabilitation may have unknowingly influenced results.<sup>42</sup> The choice of setting was only justified in five studies.<sup>43</sup>

While all included studies received approval from an ethics committee, and all but four explicitly mentioned obtaining informed consent,<sup>44</sup> ethical issues were not adequately discussed in many of the studies. Four studies did show some evidence of this reflection.<sup>45</sup> This included using a gatekeeper at recruitment,

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<sup>35</sup> Critical Appraisal Skills Programme, 2011

<sup>36</sup> Burton, 2000, O'Sullivan and Chard, 2010, Ellis-Hill, et al., 2009

<sup>37</sup> Jones, et al., 2008

<sup>38</sup> Rochette, et al., 2007, Alaszewski, et al., 2007

<sup>39</sup> Burton, 2000, Kubina, et al., 2013, Gustafsson and Bootle, 2013, O'Sullivan and Chard, 2010, Rittman, et al., 2007, Rochette, et al., 2007, Robison, et al., 2009, Jones, et al., 2008, Ellis-Hill, et al., 2009

<sup>40</sup> Barnsley, et al., 2012

<sup>41</sup> Wood, et al., 2010, Carlsson, et al., 2009

<sup>42</sup> O'Sullivan and Chard, 2010

<sup>43</sup> Erikson, et al., 2010a, Erikson, et al., 2010b, White, et al., 2012a, White, et al., 2012b, Jones, et al., 2008

<sup>44</sup> Kubina, et al., 2013, Jones, et al., 2008, Robison, et al., 2009, White, et al., 2012b

<sup>45</sup> O'Sullivan and Chard, 2010, Burton, 2000, Alaszewski, et al., 2007, Carlsson, et al., 2009

allowing researchers use judgement around potentially distressing topics,<sup>46</sup> providing debriefing time for participants,<sup>47</sup> offering participants copies of the audiocassette after completion of the study,<sup>48</sup> and providing contact with a support centre if needed.<sup>49</sup>

**Table 2.1.2: Methodological quality of included studies**

Authors	CASP Questionnaire*									
	1	2	3	4	5	6	7	8	9	10
Alaszewski et al., 2007	X	X	X	X	X		X	X	X	
Barnsley et al., 2012	X	X	X	X	X		X	X	X	X
Burton et al., 2000	X	X	X		X		X	X	X	X
Carlsson et al., 2009	X	X	X	X	X	X	X	X	X	X
Dickson et al., 2008	X	X	X	X	X		X	X	X	X
Ellis-Hill et al., 2009	X	X		X			X	X	X	X
Erikson et al., 2010a	X	X	X	X	X		X	X	X	X
Erikson et al., 2010b	X	X	X	X	X		X	X	X	X
Gustafsson and Bootle 2013	X	X		X	X		X	X	X	X
Jones et al., 2008	X	X	X	X	X			X	X	X
Kubina et al., 2013	X	X	X	X	X			X	X	X
O'Sullivan and Chard 2010	X	X	X	X	X	X	X	X	X	X
Rittman et al., 2007	X	X		X			X		X	X
Robison et al., 2009	X	X		X				X	X	X
Rochette et al., 2007	X	X	X	X	X		X	X	X	X
White et al., 2012a	X	X		X	X		X	X	X	X
White et al., 2012b	X	X		X	X			X	X	X
Wood et al., 2010	X	X	X	X	X	X	X	X	X	X
<p>“X” indicates clear evidence reported in text of meeting quality criterion</p> <p><b>* CASP Key<sup>50</sup></b></p> <p>1= Was there a clear statement of the aims of the research?</p> <p>2= Is a qualitative methodology appropriate?</p> <p>3= Was the research design appropriate to address the aims of research?</p> <p>4= Was the recruitment strategy appropriate to the aims of the research?</p> <p>5= Was the data collected in a way that addressed the research issue?</p> <p>6= Has the relationship between researcher and participants been adequately considered?</p> <p>7= Have ethical issues been taken into consideration?</p> <p>8= Was the data analysis sufficiently rigorous?</p> <p>9= Is there a clear statement of findings?</p> <p>10= How valuable is the research</p>										

<sup>46</sup> Alaszewski, et al., 2007

<sup>47</sup> O'Sullivan and Chard, 2010

<sup>48</sup> Burton, 2000

<sup>49</sup> Carlsson, et al., 2009

<sup>50</sup> Critical Appraisal Skills Programme, 2011

## 2.2 Synthesis of the Identified Themes

The research team analysed key themes across all the studies reviewed (a metasynthesis). Four themes that were perceived to act as barriers or facilitators to community re-integration for individuals in the first year after stroke were identified from the included studies. Themes and subthemes identified as part of this meta-synthesis are presented in Table 2.2.1 with evidence from the original texts. The themes are:

- Primary effects of stroke
- Personal factors
- Social factors
- Relationship with professionals

**Table 2.2.1: Process of thematic analysis**

Category	Subthemes	Selected examples from primary studies
<b>Primary Effects of Stroke</b>		<ul style="list-style-type: none"> <li>• “difficulties in using a hand, fatigue, speech or memory problems...are a barrier to work”(Alaszewski et al., 2007)</li> <li>• “For some, the reduction was related to mobility problems”(Rochette et al., 2007)</li> <li>• “lost the capacity to perform functions that were fundamental to the tasks involved”(Robison et al., 2009)</li> <li>• “uncertainty...related...to the fluctuations in their ability in everyday life”(Carlsson et al., 2009)</li> </ul>
<b>Personal Factors</b>		
	Perseverance	<ul style="list-style-type: none"> <li>• “merits of traits they perceived in themselves such as optimism, determination and perseverance”(Robison et al., 2009)</li> <li>• “persevere through the symptoms of fatigue in order to maintain participation in valued roles”(White et al., 2012a)</li> <li>• “success in achieving an intended goal through their personal perseverance”(Jones et al., 2008)</li> <li>• “Hope appeared to be a major feature of emotional recovery in the first few weeks”(Burton 2000)</li> </ul>
	Emotional challenges	<ul style="list-style-type: none"> <li>• “Establishing independence required participants to transition from feeling overwhelmed to gaining control”(Wood et al., 2010)</li> <li>• “Visits into the community appeared to be limited by reduced confidence”(Gustafsson and Bootle, 2013)</li> <li>• “participation in this valued role was challenged by a lack of confidence”(White et al., 2012b)</li> <li>• “attributed to physical and psychological barriers, including fear of falling, being afraid to leave the house”(Rittman et al., 2007)</li> <li>• “changes in how their voice sounded which also had a negative impact on self-identity”(Dickson et al., 2008)</li> </ul>
	Meaning attached to activities	<ul style="list-style-type: none"> <li>• “People who had meaningful destinations were more likely to travel outdoors”(Barnsley et al., 2012)</li> <li>• “the social meaning of those activities appeared to be missing”(Burton 2000)</li> <li>• “the meanings participants gave to activities inspired and challenged them to engage more fully in their rehabilitation process”(Erikson et al., 2010a)</li> </ul>

	<ul style="list-style-type: none"> <li>• “a strategy to avoid excessive fatigue in order to prevent another stroke”(Rochette et al., 2007)</li> <li>• “Why did I have the stroke?” and “Will I have another one?” For some people this lack of knowledge led to living a life affected by uncertainty”(Ellis-Hill et al., 2009)</li> </ul>
Adaptability of the individual	<ul style="list-style-type: none"> <li>• “able to resume a favoured pastime and take pleasure from it by being a little inventive, accepting help, scaling down the scope of the activity or tolerating lesser performance”(Robison et al., 2009)</li> <li>• “Participants managed their lack of confidence by adjusting expectations of their abilities”(White et al., 2012b)</li> <li>• “The ability to re-evaluate and find new values and goals in life was seen as an important strategy when giving up earlier pursuits was the only option”(Carlsson et al., 2009)</li> </ul>
<b>Social Factors</b>	
Sense of belonging versus perceived stigmatisation	<ul style="list-style-type: none"> <li>• “resistant because bus drivers and other passengers did not understand their disabilities”(Barnsley et al., 2012)</li> <li>• “feelings of social stigma”(Rittman et al., 2007)</li> <li>• “they were now treated differently and experienced discomfort at being accorded sympathy”(Dickson et al., 2008)</li> <li>• “stigmatization from the broader community”(White et al., 2012a)</li> <li>• “Belonging was characterized as feeling part of a group and valuing engagement in its activities”(Kubina et al., 2013)</li> </ul>
Support and dependency	<ul style="list-style-type: none"> <li>• “The assistance received from family and friends was positive”(Gustafsson and Bootle, 2013)</li> <li>• “All five participants expressed the need for support to ensure that they re-engaged in their leisure activities”(O'Sullivan and Chard, 2010)</li> <li>• “family and friends supported them”(Kubina et al., 2013)</li> <li>• “People in the sphere of influence positively influenced outdoor travel if practical support was available”(Barnsley et al., 2012)</li> <li>• “Feelings of needing help and direction to perform mundane tasks, such as dressing and sitting, provoked negative reactions in all informants”(Burton 2000)</li> <li>• “Participants with smaller social networks often felt like a burden to others, had low motivation and fewer opportunities to engage in meaningful activity”(Wood et al., 2010)</li> <li>• “Connected participants reported contributing to their environment in different ways”(Rittman et al., 2007)</li> </ul>
Environmental factors	<ul style="list-style-type: none"> <li>• “unable to manage the additional walking distances required to get to and from collection points”(White et al., 2012b.)</li> <li>• “driving as a key to return to independence post-stroke.”(O'Sullivan and Chard, 2010)</li> <li>• “due to limited community access”(Gustafsson and Bootle, 2013)</li> <li>• “Needing to negotiate steep stairs and find a seat quickly”(Barnsley et al., 2012)</li> </ul>

Professionals	
“Being supported versus being abandoned”	<ul style="list-style-type: none"> <li>• “most people perceived that this early therapeutic support had helped them”(Robison et al., 2009)</li> <li>• “Other participants described the motivation and encouragement provided by therapists”(Jones et al., 2008)</li> <li>• “Some had experienced skilled stroke care and rehabilitation that they thought had positively affected their coping process”(Carlsson et al., 2009)</li> <li>• “losing momentum was a consequence of delays and discontinuity of therapy”(Ellis-Hill et al., 2009)</li> </ul>
“Being in the picture versus being in the dark”	<ul style="list-style-type: none"> <li>• “Several participants took the advice of health professionals quite literally”(Barnsley et al., 2012)</li> <li>• “inconsistencies and confusion surrounding return to driving processes”(White et al., 2012b)</li> <li>• “People often felt in the dark about how to manage their physical recovery”(Ellis-Hill et al., 2009)</li> </ul>
“Rehabilitation setting creates uncertainty”	<ul style="list-style-type: none"> <li>• “They described feeling controlled by the therapists regarding which direction therapy would take and the activities which were to be practiced”(Jones et al., 2008)</li> <li>• “Some reported that professional input was artificial, where the context of therapeutic activity that was designed to help them undertake specific activities bore little resemblance to their own home environments”(Burton 2000)</li> <li>• “some activities at the rehabilitation clinic neither bore relation to their actual pre-stroke work tasks nor were challenging enough to match the complexity of tasks they needed to return to work”(Erikson et al., 2010b)</li> </ul>

## Primary effects of stroke

Participants in the selected studies discussed a number of primary effects of stroke, and how they acted as barriers to community re-integration. These effects included physical limitations, for example, mobility deficits, falling and impaired hand function.<sup>51</sup>

“poor mobility, loss of leg and/or hand function, poor standing tolerance and fatigue, as a reason for their inability to re-engage in active leisure activities”<sup>52</sup>

Also frequently mentioned were more invisible symptoms including communication deficits, fatigue, and impairment of cognitive function.<sup>53</sup>

“experiences of fatigue... limited their ability to resume previously valued activities”<sup>54</sup>

<sup>51</sup> Rittman, et al., 2007, Burton, 2000, Robison, et al., 2009, Gustafsson and Bootle, 2013, O'Sullivan and Chard, 2010, Rochette, et al., 2007, Alaszewski, et al., 2007

<sup>52</sup> O'Sullivan and Chard, 2010

<sup>53</sup> Dickson, et al., 2008, Alaszewski, et al., 2007, White, et al., 2012a, O'Sullivan and Chard, 2010, Rittman, et al., 2007, Robison, et al., 2009

<sup>54</sup> White, et al., 2012a



The relationship between severity of symptoms and community re-integration was complex, implying the interaction of several factors.

“High community integration, however, did not always coincide with high levels of motor functioning”<sup>55</sup>

Mild dysfunction could significantly affect re-integration, particularly for participants with dysarthria<sup>56</sup> or fatigue.<sup>57</sup> Fluctuating symptoms also led to uncertainty, which affected individuals’ ability to plan and participate.<sup>58</sup>

“This uncertainty about the level of fatigue that could be experienced on any given day was a significant barrier to planning ahead for social interaction”<sup>57</sup>

### Personal factors

Personal factors appeared to have a strong influence on community re-integration post stroke and were discussed in all but one study.<sup>59</sup> Several interactive personal factors have emerged and will be discussed under the following subthemes:

- Perseverance
- Emotional challenges
- Meaning attached to activities
- Adaptability of the individual

### **Perseverance:**

“Perseverance” was cited in several studies as a facilitator to participation.<sup>60</sup> It is a concept that appears to require both positive belief and continued focus on a goal.

“Greater expectations of recovery positively influenced how participants felt about outdoor travel.”<sup>61</sup>

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<sup>55</sup> Rittman, et al., 2007

<sup>56</sup> Dickson, et al., 2008

<sup>57</sup> White, et al., 2012a

<sup>58</sup> Carlsson, et al., 2009, White, et al., 2012a

<sup>59</sup> Erikson, et al., 2010a

<sup>60</sup> White, et al., 2012a, Robison, et al., 2009, Jones, et al., 2008

<sup>61</sup> Barnsley, et al., 2012

Participants discussed personality traits that were key to continued perseverance including hope, optimism, determination, stubbornness,

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competitiveness, resilience, and initiative.<sup>62</sup> Active testing of abilities with support encouraged return to activity as described by Kubina and colleagues.

“There was a cyclical relationship between incremental risk-taking in activities and success, hope for full recovery and further risk taking”<sup>63</sup>

In contrast low expectation for recovery led to withdrawal from pre-stroke activities.<sup>64</sup> A passive sense of hope did not seem to be sufficient to facilitate re-integration.

“Survivors who experience low community integration express an outlook on life that consists of taking things easy, hoping they will improve physically as time goes by, eventually being able to return to important activities”<sup>65</sup>

### ***Emotional challenges:***

Participants’ ability to persevere towards community re-integration was challenged by several emotional barriers. They wished to view themselves as capable,<sup>66</sup> but the struggle of recovery after stroke disturbed their sense of self and led to fluctuating confidence.<sup>67</sup> Wood and colleagues describe the process of community re-integration after stroke as “non-linear” for this reason.<sup>68</sup> The sudden nature of experiencing a stroke left people feeling unprepared and uncertain.<sup>69</sup>

“Uncertainty was often perceived as extending into the future, when responses to problems or crises could not be visualized or anticipated”<sup>70</sup>

The loss of control experienced post stroke was associated with changes in self-identity, self-consciousness, reduced self-esteem and reduced confidence.<sup>71</sup>

“Thus people were limited by the fact that they had lost confidence in their bodies and felt uncomfortable by the sensations experienced even though they could achieve the activity.”<sup>72</sup>

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<sup>62</sup> Burton, 2000, Jones, et al., 2008, Robison, et al., 2009, Carlsson, et al., 2009, Rittman, et al., 2007, Dickson, et al., 2008, White, et al., 2012a, Alaszewski, et al., 2007

<sup>63</sup> Kubina, et al., 2013

<sup>64</sup> Barnsley, et al., 2012, Robison, et al., 2009, Alaszewski, et al., 2007

<sup>65</sup> Rittman, et al., 2007

<sup>66</sup> Carlsson, et al., 2009

<sup>67</sup> Gustafsson and Bootle, 2013, Rittman, et al., 2007, Wood, et al., 2010

<sup>68</sup> Wood, et al., 2010

<sup>69</sup> Burton, 2000, Carlsson, et al., 2009, Rittman, et al., 2007

<sup>70</sup> Burton, 2000

<sup>71</sup> Burton, 2000, Jones, et al., 2008, Wood, et al., 2010, Robison, et al., 2009, Rittman, et al., 2007, Rittman, et al., 2007, Dickson, et al., 2008, Robison, et al., 2009, White, et al., 2012a, Gustafsson and Bootle, 2013, White, et al., 2012b

<sup>72</sup> Robison, et al., 2009

Accompanying feelings of fear, anxiety, anger and frustration could be disrupting and overwhelming and were difficult barriers to overcome.<sup>73</sup> A pre-disposition towards anxiety or worry also affected their ability to cope and re-integrate after the stroke.<sup>74</sup> Some individuals attributed their difficulties to ageing.<sup>75</sup> Although this sometimes led to a reduction in activity it also allowed changes post stroke to be viewed as normal, thus...

“ameliorating or muting altogether the effects of bodily changes on one’s sense of self”<sup>76</sup>

### ***Meaning attached to activities***

The meaning that individuals attach to certain activities has emerged as an important factor in whether or not they re-engage in those activities. In the early stages after stroke the goals of returning home, dressing and feeding independently were described as motivators across several studies.<sup>77</sup> Later on, gradual return to work and driving were two activities used by participants for benchmarking future improvements.<sup>78</sup>

Following discharge to the community setting, the act of having meaningful leisure activities and “meaningful destinations” were motivators to re-integration.<sup>79</sup> Those who attached meaning to their level of pre-stroke activity were more likely to be active post-stroke.<sup>80</sup> Meaning was important for the enjoyment of activity and helped in the setting of goals.<sup>81</sup>

“Meaningful roles, activities and relationships were fundamental to finding fulfilment and enjoyment in daily living.”<sup>82</sup>

The meaning of work in individuals’ lives also determined whether participants would successfully return to employment after their stroke.<sup>83</sup> Changes in meaning of activity were particularly evident post stroke if individuals viewed aspects of their previous lifestyles as having contributed to the stroke event.<sup>84</sup> Perceptions of stress or fatigue as a causative factor for stroke led individuals

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<sup>73</sup> Jones, et al., 2008, Robison, et al., 2009, Barnsley, et al., 2012, Burton, 2000, O’Sullivan and Chard, 2010, Dickson, et al., 2008, Carlsson, et al., 2009, Wood, et al., 2010, Rittman, et al., 2007

<sup>74</sup> Barnsley, et al., 2012, Carlsson, et al., 2009

<sup>75</sup> Dickson, et al., 2008, Rittman, et al., 2007

<sup>76</sup> Rittman, et al., 2007

<sup>77</sup> Wood, et al., 2010, Jones, et al., 2008, Burton, 2000

<sup>78</sup> Rittman, et al., 2007

<sup>79</sup> Barnsley, et al., 2012, Burton, 2000, Rittman, et al., 2007, Wood, et al., 2010, Carlsson, et al., 2009

<sup>80</sup> Rittman, et al., 2007, Barnsley, et al., 2012

<sup>81</sup> Burton, 2000, Carlsson, et al., 2009

<sup>82</sup> Wood, et al., 2010

<sup>83</sup> Alaszewski, et al., 2007, Robison, et al., 2009

<sup>84</sup> Carlsson, et al., 2009, Rochette, et al., 2007, Alaszewski, et al., 2007, Kubina, et al., 2013, Ellis-Hill, et al., 2009

to reduce their participation in work or social roles.<sup>84</sup> In contrast, this desire for secondary prevention was also associated with new activities that promoted health, including exercise.<sup>85</sup> This fear of recurrent stroke also contributed to anxiety, which as described, can be barrier to coping.<sup>86</sup>

“The respondents felt a motivation to make changes to promote their health in order to avoid a new stroke”<sup>85</sup>

### ***Adaptability of the individual***

“The adaptability of the individual”, a theme identified by Robison and colleagues, has emerged as an important concept from several studies.<sup>87</sup> It describes a person’s acceptance of change in the performance of activities in order to participate.

“Creating balance between capacity, self-identity and personal expectations was the ultimate challenge of community re-integration.”<sup>88</sup>

This first requires insight into current limitations.<sup>89</sup> Accepting appropriate help or adaptations appears to be important in coping with these limitations.<sup>90</sup> Symptom management strategies for fatigue,<sup>89</sup> adaptations for mobility<sup>91</sup> and alternative communication strategies for dysarthria (speech difficulty following stroke) were described.<sup>92</sup> As the process of community re-integration is “non-linear”,<sup>88</sup> adaptability can prevent one from becoming discouraged.<sup>89</sup> Stroke survivors needed to adjust their expectations<sup>93</sup> before “scaling down the scope of the activity”, “tolerating lesser performance”,<sup>94</sup> or when safety is paramount, “placing self-imposed restrictions”.<sup>95</sup>

“Activities of high importance for the participant seemed to have been given much consideration and adaptations that might have been previously thought of as unacceptable, became acceptable, or became necessary to keeping that activity in one’s life”<sup>96</sup>

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<sup>85</sup> Carlsson, et al., 2009

<sup>86</sup> Rochette, et al., 2007, Ellis-Hill, et al., 2009

<sup>87</sup> White, et al., 2012b, White, et al., 2012a, Rittman, et al., 2007, Dickson, et al., 2008, Kubina, et al., 2013, Burton, 2000, Carlsson, et al., 2009, O’Sullivan and Chard, 2010, Wood, et al., 2010, Robison, et al., 2009

<sup>88</sup> Wood, et al., 2010

<sup>89</sup> White, et al., 2012a

<sup>90</sup> Wood, et al., 2010, White, et al., 2012b, Robison, et al., 2009, Rittman, et al., 2007, White, et al., 2012a, Kubina, et al., 2013

<sup>91</sup> Robison, et al., 2009, Rittman, et al., 2007

<sup>92</sup> Dickson, et al., 2008

<sup>93</sup> Wood, et al., 2010, White, et al., 2012a, Dickson, et al., 2008

<sup>94</sup> Robison, et al., 2009

<sup>95</sup> White, et al., 2012b

<sup>96</sup> Kubina, et al., 2013

The inability to fulfil or adjust one's expectations was described as frustrating and demotivating.<sup>97</sup>

“Altered expectations appeared to assist participants accept their altered lifestyle and stop “battling” themselves”<sup>98</sup>

Participants needed to feel in charge of decisions to accept adaptations and changes in performance and reassess priorities.

“being in charge seemed to provide both press and support for re-engagement in valued activities”<sup>99</sup>

Having an adaptable outlook also allowed stroke survivors to “re-evaluate and find new values and goals in life”.<sup>100</sup> It allowed them to identify and take up new activities that could substitute for pre-stroke activities and provide meaning.<sup>101</sup>

## **Social Factors**

Social factors relate to the stroke survivors' interaction with other people and the community environment. They will be discussed under the following identified subthemes:

- Sense of belonging versus perceived stigmatisation
- Support and dependency
- Environmental factors

### ***Sense of belonging versus perceived stigmatisation***

Social environments were described as being either supportive, promoting a sense of belonging, or undermining, which could lead to perceived stigmatisation.<sup>102</sup> The type of environment impacted on re-integration.

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<sup>97</sup> Wood, et al., 2010

<sup>98</sup> White, et al., 2012a

<sup>99</sup> Kubina, et al., 2013

<sup>100</sup> Carlsson, et al., 2009

<sup>101</sup> O'Sullivan and Chard, 2010, Robison, et al., 2009

<sup>102</sup> Alaszewski, et al., 2007, Kubina, et al., 2013, Erikson, et al., 2010a, Dickson, et al., 2008

In the broader community participants perceived a lack of understanding about their disabilities, particularly if symptoms were “in part hidden”.<sup>103</sup> Participants with dysarthria, fatigue and physical disabilities described perceiving social stigma.<sup>104</sup> This was counterbalanced by a sense of belonging that could be created and supported through taking part in meaningful activities with others who showed flexibility.<sup>105</sup> Belonging resulted in “motivation to continue to take part in the group’s activities”<sup>106</sup> and “integration into social worlds”.<sup>107</sup>

“doing something with someone that matters supported the participants’ sense of belonging and, thus, integration into social worlds”<sup>107</sup>

The work environment could also be described as supportive or undermining.<sup>108</sup> Supportive colleagues and managers facilitated return to work, by being flexible in relation to working hours, workload, gradual return, and by helping participants to gauge changes in their abilities.<sup>109</sup> This allowed the participants to feel “an easing into belonging”.<sup>107</sup> This supportiveness was important within the context of the employment setting, for example the type of organisation.<sup>108</sup>

### ***Support and dependency***

Support from family and close friends in an important facilitator of community re-integration.<sup>110</sup> This support can take the form of practical help including transport and introducing adaptations,<sup>111</sup> or more emotional support and encouragement.<sup>112</sup> This support is largely seen as positive, but it should also allow for some autonomy.<sup>111</sup>

“People are worth their weight in gold: Gratitude for help and support”<sup>113</sup>

The associated feeling of dependency is more complex in how it affects re-integration. Feeling dependent in everyday tasks provoked negative emotions in many participants.<sup>114</sup> It could lead to tension and disruption of relationships.<sup>115</sup> Being dependent on others also created a practical barrier to

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<sup>103</sup> Barnsley, et al., 2012, Carlsson, et al., 2009

<sup>104</sup> Dickson, et al., 2008, White, et al., 2012a, Rittman, et al., 2007, Rochette, et al., 2007

<sup>105</sup> Erikson, et al., 2010a, Kubina, et al., 2013, Rittman, et al., 2007, Robison, et al., 2009

<sup>106</sup> Kubina, et al., 2013)

<sup>107</sup> Erikson, et al., 2010a).

<sup>108</sup> Alaszewski, et al., 2007

<sup>109</sup> Alaszewski, et al., 2007, Carlsson, et al., 2009, Robison, et al., 2009, Erikson, et al., 2010a

<sup>110</sup> Kubina, et al., 2013, Rittman, et al., 2007, Gustafsson and Bootle, 2013, O’Sullivan and Chard, 2010, Barnsley, et al., 2012, Robison, et al., 2009, Burton, 2000

<sup>111</sup> Barnsley, et al., 2012, Kubina, et al., 2013

<sup>112</sup> Erikson, et al., 2010a, Rittman, et al., 2007

<sup>113</sup> O’Sullivan and Chard, 2010

<sup>114</sup> Burton, 2000

<sup>115</sup> Dickson, et al., 2008

community re-integration, as participants had to work around others' schedules.<sup>116</sup> Another important concept discussed by Erikson et al is "the burden of burden".<sup>117</sup>

"Perceiving the burden of caregiving on their relatives' burden, without being able to change the situation, the participants described how the stress of their new situation after the stroke disrupted their social world"<sup>117</sup>

Having a smaller social network could worsen this feeling of being a burden.<sup>118</sup> In these studies some participants tried to relieve the burden on their families by hiding their difficulties or withdrawing from social interaction.<sup>119</sup> Feelings of dependency can also be a motivator.<sup>120</sup>

"Sometimes the perception of dependency, especially with a deeply personal task such as going to the toilet, acted as a spur"<sup>120</sup>

If stroke survivors were able to reciprocate, and help others, this could reduce their sense of burden.<sup>121</sup> It was associated with...

"motivation to continue to do self-identifying activities despite a fair degree of challenge."<sup>122</sup>

### ***Environmental factors***

Environmental factors were primarily discussed in relation to community access.<sup>123</sup> Seven studies described returning to driving as an important facilitator of community re-integration.<sup>124</sup> This was particularly true when environmental constraints and lack of support restricted community access. Difficulties with public transport reported include the distance from collection points, the need to find a seat, and steep steps on buses.<sup>125</sup>

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<sup>116</sup> Gustafsson and Bootle, 2013, O'Sullivan and Chard, 2010, Burton, 2000

<sup>117</sup> Erikson, et al., 2010a

<sup>118</sup> Wood, et al., 2010

<sup>119</sup> Carlsson, et al., 2009

<sup>120</sup> Jones, et al., 2008

<sup>121</sup> Rittman, et al., 2007, Wood, et al., 2010, Erikson, et al., 2010a, Kubina, et al., 2013

<sup>122</sup> Kubina, et al., 2013

<sup>123</sup> Gustafsson and Bootle, 2013, Rittman, et al., 2007

<sup>124</sup> Robison, et al., 2009, White, et al., 2012, Barnsley, et al., 2012, O'Sullivan and Chard, 2010, Wood, et al., 2010, Rittman, et al., 2007, Barnsley, et al., 2012, Rochette, et al., 2007

<sup>125</sup> White, et al., 2012, Barnsley, et al., 2012



### ***Relationship with professionals***

The final theme that emerged from the analysis was professionals, who could act as barriers or facilitators to community re-integration post stroke. Three components of this theme were identified:

- “Being supported versus being abandoned”<sup>126</sup>
- “Being in the picture versus being in the dark”<sup>126</sup>
- “Rehabilitation setting creates uncertainty”<sup>127</sup>

#### ***“Being supported versus being abandoned”<sup>128</sup>***

A positive experience of early stroke care facilitated longer-term coping and recovery.<sup>129</sup> This is described by Ellis-Hill and colleagues in their theme “being supported versus being abandoned”.<sup>128</sup> The opportunity to share experiences with other patients and professionals in a rehabilitation unit was viewed as helpful.<sup>130</sup> Positive relationships with therapists led to feelings of hope, confidence and momentum.<sup>131</sup>

“therapy helped to facilitate progress...by responding to problems and solving each difficulty as it arose”<sup>132</sup>

Those with mobility deficits placed importance on physical exercise in the rehabilitation gym”.<sup>133</sup> People with dysarthria viewed the speech and language therapist as the primary professional source of support.<sup>134</sup> Community-based services, including follow-up medical appointments, continuing therapy, home modifications and equipment were considered “valuable”.<sup>133</sup> Treatment delays or being unprepared for discharge were associated with a sense of “losing momentum.”<sup>128</sup>

#### ***“Being in the picture versus being in the dark”<sup>128</sup>***

Participants discussed the lack of advice given by inpatient professionals about return to driving processes, alternative transport options,<sup>135</sup> fatigue management, return to work, and availability of follow-up community

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<sup>126</sup> Ellis-Hill, et al., 2009

<sup>127</sup> Erikson, et al., 2010b

<sup>128</sup> Ellis-Hill, et al., 2009

<sup>129</sup> Robison, et al., 2009, Carlsson, et al., 2009

<sup>130</sup> Carlsson, et al., 2009

<sup>131</sup> Jones, et al., 2008, Ellis-Hill, et al., 2009

<sup>132</sup> Jones, et al., 2008

<sup>133</sup> Gustafsson and Bootle, 2013

<sup>134</sup> Dickson, et al., 2008

<sup>135</sup> White, et al., 2012b

services.<sup>136</sup> When clear information was provided it was described to have an empowering effect.<sup>135</sup>

“Participants who were informed of return to driving processes were empowered to take responsibility to negotiate the steps required to resume this valued role”<sup>135</sup>

In contrast, unclear information could be counterproductive. For example, Barnsley and colleagues found that health professionals had advised many of the participants not to cross the road unsupervised. Several participants took this advice literally and avoided venturing outdoors alone even when they were capable.<sup>137</sup> Other advice given by therapists was considered to be unclear, as it could be interpreted in different ways.<sup>138</sup>

“One problem appeared to be the lack of review; advice given early in a rehabilitation program may be restrictive and counterproductive later”<sup>137</sup>

***“Rehabilitation setting creates uncertainty”<sup>139</sup>***

It emerged from several studies that participants had difficulty relating rehabilitation in an inpatient or clinical setting to meaningful activities and goals in the community.<sup>140</sup> Many tests and therapeutic activities were seen as artificial, bearing little resemblance to home and work environments to which participants were hoping to re-integrate.<sup>141</sup> Several people felt that therapists made the decisions about the focus of therapy after stroke. This led to them feeling “controlled”.<sup>142</sup> Robison et al concluded that...

“the failure of physiotherapy to engage effectively with their desire to resume previously valued activities is evident”<sup>143</sup>

Some participants had the opportunity to practice activities with professionals in the home environment and they viewed this as important.<sup>144</sup> Otherwise the change in environment on discharge home was seen to reduce “the sense of momentum built up in hospital”.<sup>138</sup>

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<sup>136</sup> White, et al., 2012a; Robison, et al., 2009; Gustafsson and Bootle, 2013; Ellis-Hill, et al., 2009

<sup>137</sup> Barnsley, et al., 2012

<sup>138</sup> Ellis-Hill, et al., 2009

<sup>139</sup> Erikson, et al., 2010b

<sup>140</sup> Erikson, et al., 2010b, Erikson, et al., 2010a, Burton, 2000, Jones, et al., 2008, Robison, et al., 2009, Gustafsson and Bootle, 2013, Ellis-Hill, et al., 2009

<sup>141</sup> Erikson, et al., 2010b, Burton, 2000, Erikson, et al., 2010a

<sup>142</sup> Jones, et al., 2008

<sup>143</sup> Robison, et al., 2009

<sup>144</sup> Gustafsson and Bootle, 2013

## **2.3 Systematic Review Discussion**

### **Statement of principal findings**

Community re-integration in the first year after stroke involves “getting back to real living”. It is a non-linear and complex process.<sup>145</sup> Many interactive factors can facilitate or inhibit this re-integration. Although the primary effects of the stroke are important, personal and social factors also affect coping. An individual’s ability to persevere in their recovery, overcome emotional disruptions, and attach meaning to activities can facilitate their re-integration into the community. Accepting necessary help and adaptations also helps them to overcome residual limitations. Social support from family and friends is vital. Dependency, however, is associated with diverse emotional consequences that can challenge a stroke survivor’s sense of self. The broader community can encourage a sense of belonging in a person who has experienced a stroke. Conversely others can promote feelings of stigma. This depends on the visibility of symptoms and the level of understanding among the general population. Health care professionals have been described as both facilitators and barriers to community re-integration. Clear and practical advice can empower people to return to valued roles after stroke. Participants found it difficult to apply activities practiced in the clinical setting to their home lives. This undoubtedly inhibited community re-integration.

### **Findings in the context of other studies**

Participants of the included studies perceived the primary effects of their stroke to be barriers for community re-integration. This is reflected in other qualitative reviews.<sup>146</sup> The relationship between severity of symptoms and community re-integration appears to be complex. A systematic review of randomised controlled trials concluded that deterioration in social and leisure activities is associated with several personal characteristics, including female gender, younger age and increased levels of education.<sup>147</sup> This supports the finding of our review that a range of factors is associated with an individual’s resumption of valued activities and participation in community life post stroke.

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<sup>145</sup> Wood, et al., 2010

<sup>146</sup> Lawrence 2010, Nicholson, et al., 2013

<sup>147</sup> Bhogal, et al., 2003

Perseverance as a theme emerged from included studies in this review. We concluded that this perseverance required general optimism, expectations of recovery and active working towards goals. Bright and colleagues identified three key forms of “hope” after stroke: “an inner state of being”, “outcome-oriented hope” and “the active process of hope”. They proposed that “the cognitive aspect of hope must be accompanied by action”, which involves participating in activities to maximise recovery.<sup>148</sup> This mirrors the findings from our review.

The concepts of self-identity and self-efficacy are frequently discussed in qualitative research exploring the experience of living with stroke.<sup>149</sup> Self-consciousness has been found to lead to withdrawal from physical and social activity.<sup>150</sup> Other qualitative work suggests that in the clinical setting stroke survivors experience an overly emphasised focus on rehabilitation of physical needs. They feel that nonphysical needs, including help to deal with social and psychological consequences of stroke are somewhat neglected.<sup>151</sup> One way that stroke survivors have found to reduce this impact on their sense of self is to explain any long-term effects of stroke as the effects of ageing.<sup>152</sup>

The meaning that individuals attach to activities could be a motivator to participation. Other authors have described how the desires to carry out daily tasks and return to driving are motivators to physical activity.<sup>153</sup> The meaning attached to activities can also be related to causation beliefs about stroke. Several systematic reviews discuss how a fear of stroke recurrence can lead to avoidance of activities including exercise, stressful situations, work and holidaying abroad.<sup>154</sup>

Sarre and colleagues discuss adjustment after stroke in terms of “practical and mental strategies”.<sup>155</sup> We found that stroke survivors need to be in charge of the decision to accept help or adjust their expectations and in doing so they can facilitate their own participation. Thus we conclude that cognitive adjustment is required for successful practical adjustment. Sarre and colleagues also describe adaption as a “difficult process of reconciliation between the past and present selves”, rather than an endpoint.<sup>155</sup> This reflects the complexity of our theme “adaptability of the individual”.

<sup>148</sup> Bright, et al., 2011

<sup>149</sup> Sarre, et al., 2013, Salter, et al., 2008

<sup>150</sup> Nicholson, et al., 2013, Bhogal, et al., 2003

<sup>151</sup> Peoples, et al., 2011

<sup>152</sup> Lawrence 2010

<sup>153</sup> Nicholson, et al., 2013

<sup>154</sup> Nicholson, et al., 2013, Lawrence 2010, Sarre, et al., 2013

<sup>155</sup> Sarre, et al., 2013

The broader community can contribute to whether a stroke survivor feels a sense of belonging or stigma. The problem of public ignorance surrounding issues of stroke, particularly invisible symptoms, has been highlighted in several qualitative reviews in addition to ours.<sup>156</sup> A balance also needs to be struck between recognising stroke-related deficits and treating people after their stroke “as normal”.<sup>157</sup> Our findings suggest that doing meaningful activities with others in a social context can facilitate gradual return to participation.

Social support after stroke comes in different guises: practical, emotional and moral.<sup>158</sup> Emotional support from family members is specifically associated with better functional outcome in the non-acute stage of stroke.<sup>159</sup> Our review and other qualitative reviews have described the emotional consequences of feeling like a burden on one’s family.<sup>157</sup> Our review considers gratitude for social support and negative feelings of dependency as two sides of the same coin. Opportunities that allow the stroke survivor to reciprocate and contribute could mediate the “burden of burden”.<sup>160</sup>

Relationships with professionals have been described throughout the literature as having both positive and negative impacts on individuals after stroke.<sup>156</sup> Many stroke survivors value being treated as individuals,<sup>161</sup> while inadequate access to therapy can hamper recovery.<sup>157</sup> Information provided by professionals is regarded as a valuable resource but was found wanting by participants in several studies.<sup>158</sup> Defining recovery in terms of the individual’s goals is very important in helping them resume valued aspects of their lives.<sup>162</sup> It has emerged that this does not always occur in practice. The purpose of rehabilitation activities can be difficult to understand if stroke survivors are not actively involved in the process.<sup>157</sup>

## **Clinical implications**

Traditionally the clinical focus has been on the physical consequences (sequelae) of stroke. This review has highlighted the importance of the psychological concepts of self-identity and self-confidence in facilitating community re-integration. Emotional consequences of stroke should therefore be considered from an early stage. Access to psychological services in the community could help individuals to re-construct their sense of self and surmount emotional barriers.

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<sup>156</sup> Lawrence 2010, Sarre, et al., 2013

<sup>157</sup> Lawrence 2010

<sup>158</sup> Sarre, et al., 2013

<sup>159</sup> Bhogal, et al., 2003

<sup>160</sup> Erikson, et al., 2010a

<sup>161</sup> Peoples, et al., 2011

<sup>162</sup> Salter, et al., 2008, Lawrence 2010, Nicholson, et al., 2013

This review also highlights the importance of having meaningful activities in the community. It has also been shown that stroke survivors have difficulty in linking therapeutic activities to valued roles. Meaningful community activities that are important to the individual should be discussed in the early stages of rehabilitation and the stroke survivor should define clear goals themselves. Therapeutic activity should then reflect these goals in a way that is as similar to real-life situations as possible.

The artificiality of the rehabilitation setting has also been highlighted as a problem. The practice of “early supported discharge”, where patients receive rehabilitation in their own homes, has received much attention in recent literature. It has been shown to reduce long-term dependency after stroke and is recommended for those with mild to moderate stroke severity.<sup>163</sup> The findings of this literature review support the concept of receiving rehabilitation in a familiar environment. Practice of community ambulation may also be beneficial and warrants further investigation in clinical trials.

Clear and locally relevant advice should be provided by health care professionals to facilitate aspects of community re-integration including return to driving processes, return to work, transport options and fatigue management strategies. Advice to restrict particular activities for safety reasons should be re-evaluated at follow-up assessments as appropriate. Clear information about home exercises and follow-up services should be provided to minimise anxiety and increase perceived control for the individual. It should also be considered when providing advice about secondary prevention, that fear of recurrent stroke is a significant cause of anxiety for many individuals.

This systematic review has highlighted wider clinical implications around the need for increased public awareness, especially with regard to the more invisible consequences of stroke. Targeting employers and staff of transport services and public amenities could facilitate a smoother return to work, and previously valued activities for individuals after stroke.

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<sup>163</sup> Fisher, et al., 2011

## **Strengths and weaknesses of the review**

This systematic review provides a synthesis of data from multiple sources, allowing us to triangulate findings. In addition, the methodological quality and rigour of each study was considered and the credibility of individual conclusions was established. The qualitative methodology has allowed us to examine in-depth factors related to community re-integration, from the viewpoint of stroke survivors themselves. Other systematic reviews of qualitative work have focussed on general experiences after stroke.<sup>164</sup> Those who examined barriers and facilitators did so for specific activities rather than community re-integration as a whole.<sup>165</sup> This piece of work focuses on the first year after stroke and draws on a broad range of detailed experiences to provide a clear picture of factors associated with community re-integration. In addition, this review provides a synthesis of findings from a variety of cultural and clinical populations. Included studies represent experiences of those with mild stroke,<sup>166</sup> fatigue,<sup>167</sup> and dysarthria,<sup>168</sup> as well as the general recently discharged stroke survivor population. It includes participants from a variety of age categories, across six primarily English-speaking countries. This has improved the transferability of findings to community settings, in the first year after stroke.

There are some limitations to this review. The majority of the included studies report excluding individuals with severe communication or cognitive deficits.<sup>169</sup> Only one study deals specifically with the consequences of communication deficits post stroke.<sup>168</sup> This may have resulted in the experiences of particular individuals being under represented in this review.

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<sup>164</sup> Bright, et al., 2011, Sarre, et al., 2013, Salter, et al., 2008, Lawrence 2010

<sup>165</sup> Nicholson et al.

<sup>166</sup> Carlsson, et al., 2009, Rochette, et al., 2007

<sup>167</sup> White, et al., 2012a

<sup>168</sup> Dickson, et al., 2008

<sup>169</sup> Wood, et al., 2010, Gustafsson and Bootle, 2013, Kubina, et al., 2013, O'Sullivan and Chard, 2010, Rochette, et al., 2007, White, et al., 2012a, White, et al., 2012b, Ellis-Hill, et al., 2009, Jones, et al., 2008, Barnsley, et al., 2012, Carlsson, et al., 2009, Erikson, et al., 2010b, Erikson, et al., 2010a

Access to services has been found to be a motivator to community re-integration, as described by the theme “being supported versus being abandoned”. Contextual detail is provided in some studies to allow us to determine transferability to the local clinical setting. It remains unclear however, if research participants had more or less access to particular services than the average stroke survivor in the Irish setting. In particular Erikson and colleagues describe a workplace training programme and Barnsley and colleagues describe a one-on-one physiotherapy/ occupational therapy intervention to increase outdoor travel.<sup>170</sup> Neither of these interventions are currently routine practice in Ireland.

It is essential that qualitative researchers recognise and highlight their own influence on the data collection and analysis process, a quality known as reflexivity.<sup>171</sup> This was found to be lacking in many of the included studies.<sup>172</sup> This leaves us unable to evaluate researcher bias in the original findings. Furthermore, the interpretation of findings may have been unknowingly influenced by the authors’ experiences and backgrounds. Both authors of this review are physiotherapists with experience working with individuals post stroke.

Finally, the process of qualitative meta-synthesis is not well defined and the methodology continues to develop. The use of a checklist approach to critical appraisal within qualitative research remains controversial. Acknowledging this, the process of meta-synthesis may facilitate the incorporation of qualitative research findings into evidence-based practice. The methodology of this review was based on previously published descriptions of such a process.<sup>173</sup>

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<sup>170</sup> Erikson, et al., 2010b, Barnsley, et al., 2012

<sup>171</sup> Kuper, et al., 2008

<sup>172</sup> Erikson, et al., 2010b, Erikson, et al., 2010a, Burton, 2000, Jones, et al., 2008, Robison, et al., 2009, Gustafsson and Bootle, 2013, Ellis-Hill, et al., 2009, White, et al., 2012b, White, et al., 2012a, Rittman, et al., 2007, Dickson, et al., 2008, Kubina, et al., 2013, Alaszewski, et al., 2007, Barnsley, et al., 2012, Rochette, et al., 2007

<sup>173</sup> Bondas and Hall, 2007, Campbell, et al., 2003



## **Areas for further research**

This review focused on experiences in the first 12 months after stroke. Subsequent qualitative reviews could explore factors associated with community re-integration in the later stages. This could highlight the changing needs of stroke survivors over time.

Of the identified studies that explored community re-integration in the first year post stroke, none included persons with aphasia. Research is needed to highlight the particular experiences of this under represented group as they transition to the community. Qualitative researchers investigating this population would require sufficient expertise in the area of communication deficits for practical and ethical reasons.

The benefit of early supported discharge and providing rehabilitation to individuals post stroke in their home setting has been established. Interventions that provide rehabilitation in other familiar community environments, including the practice of community ambulation should be investigated with clinical trials.

This review has found that stroke survivors can experience a sense of stigma both in the workplace and the broader community. Knowledge and perceptions surrounding the consequences of stroke among employers and the general public would need to be investigated to examine the root of this perceived stigma.

### **3. Results: National Survey of Stroke Survivors**

#### **3.1 Survey Characteristics**

Data were collected between June and October 2013 in the form of paper questionnaires and online survey responses.

#### **Data Analysis**

All data were inputted into a spreadsheet. Categorical data were coded. Continuous data were entered in numerical format and open responses were transcribed unchanged. Quantitative data were analysed using IBM SPSS Statistics Version 20.0. Descriptive analysis was carried out; frequencies and descriptive statistics were generated. Mean and standard deviations (SD) were calculated for normally distributed continuous variables, while median and interquartile ranges (IQR) were calculated for non-parametric variables. Associations were investigated across relevant variables using chi-squared tests, t-tests and Mann Whitney-U tests as appropriate. Statistical tests were performed at the 95% confidence level. A priori subgroup analysis was performed. For example the effects of stroke on finances and employment were analysed separately for participants younger and older than 66.

Open responses were qualitatively analysed through repeated readings and coded into themes. Relevant quotations were selected as supporting evidence for statements, or where it was felt that the meaning of the response was lost in coding. Where specific details could potentially identify individuals, they are omitted from the quotation and the omission is indicated.

#### **Response rates**

Of the 250 paper questionnaires that were distributed to stroke survivors, 163 were completed and returned. It is not known if any of these 250 individuals decided to complete the survey online. The response rate for the paper questionnaires was 65%. These responses represent members of 18 stroke support groups nationally, four groups run by non-statutory organisations, and 7 areas in which community health-care professionals acted as gatekeepers. Sixty of these questionnaires were completed during face-to-face interviews with researchers while stroke survivors completed 103, either independently or with the assistance of family members. In addition, 37 stroke survivors have completed the online version of the questionnaire. On initial analysis of responses 4 questionnaires were excluded on the basis that they were completed by carers of stroke survivors under the age of 18 or living in full time residential care. In this report results will be presented based on 196 responses (161 paper, 35 online).

## Characteristics of respondents

Respondents experienced a stroke between 3 months and 19 years previous to the survey with the median number of months since their most recent stroke being 28 months (IQR 38 months). Twenty-seven of the respondents (13%) have experienced multiple strokes. Although the aim of this study was to describe experiences up to 5 years after stroke, 15 people responded to the survey who experienced their stroke between 5 and 7 years ago, and a further 10 respondents experienced their stroke more than 7 years ago. On initial inspection, exclusion of the data from these 25 individuals does not change the overall findings significantly. For the purposes of this report all data has been included in quantitative and qualitative analyses and all results will be presented.

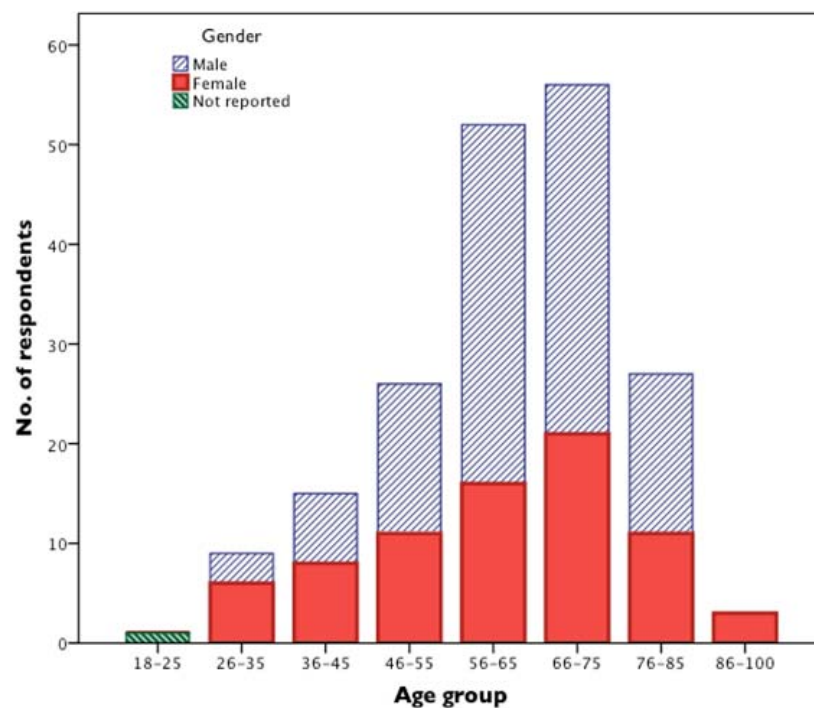
Fifty-nine per cent of respondents were men. Respondents were aged between 24 and 89 years with a mean age of 61.9 (SD 13.9). Females were broadly dispersed between age categories while males were mostly concentrated in the 56-75 age group (68% of males). See Figure 3.1.1 for distribution of males and females by age group. Thirty-eight per cent of respondents live in Dublin, one third are from other towns or cities in Ireland and twenty-seven per cent are from rural areas. Figure 3.1.2 presents the geographic distribution of our sample compared to the overall distribution of the national population.

The 35 online respondents represent a significantly younger group ( $p < 0.001$ )<sup>174</sup>, with fewer of them being dependent for personal care after their stroke ( $p = 0.005$ ). They had a mean age of 46.5 (SD 14) and all had experienced their strokes within the last 6 years. Table 3.1.1 presents differences in the demographic characteristics of respondents to the paper and online versions of the questionnaire.

Despite experiencing multiple problems after stroke over half of respondents (58%) report being satisfied with the overall recovery they have made. A quarter of respondents were very satisfied, twelve per cent were dissatisfied and only three per cent report being very dissatisfied with their overall recovery since their stroke. Thirty-seven per cent of individuals feel they were happy with their level of involvement in decision-making during their care and treatment, while a quarter of respondents feel they were not as involved as they should have been.

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<sup>174</sup>  $p < 0.05$  demonstrates a statistically significant difference at the 95% confidence level



**Figure 3.1.1: Distribution of age group by gender**

Source: CSO, 2011<sup>175</sup>

**Figure 3.1.2: Geographical distribution of sample compared to national population**

<sup>175</sup> Central Statistics Office, 2011

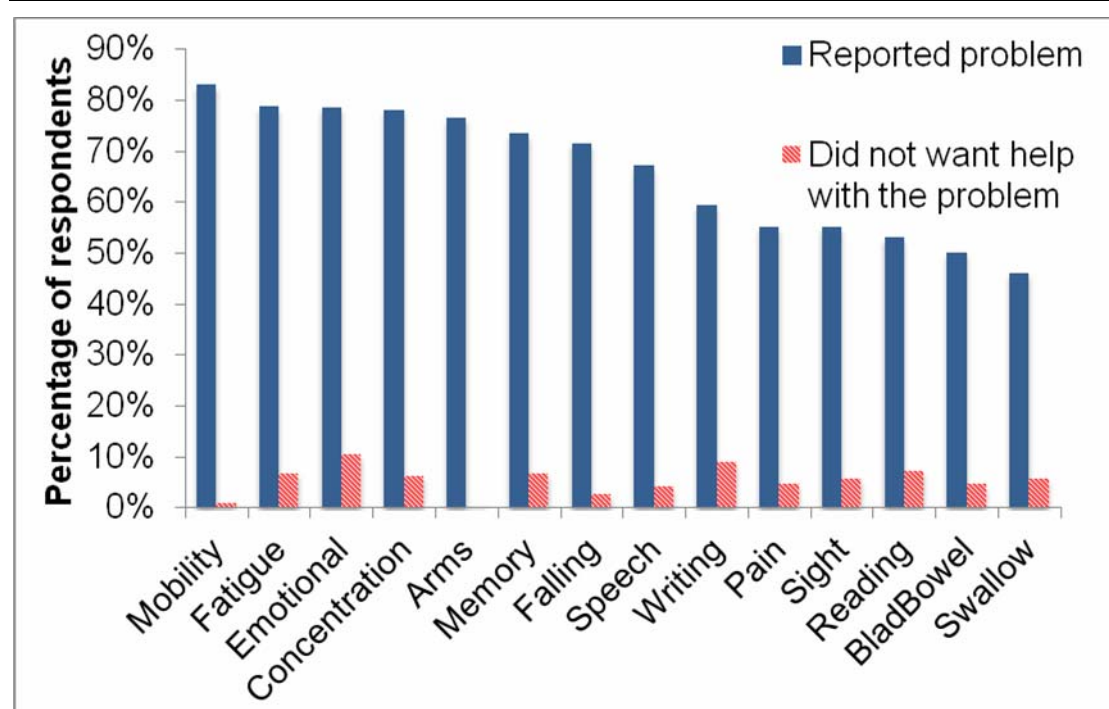
**Table 3.1.1: Respondent Characteristics**

	Number of respondents (%)		
	Paper (n=161)	Online (n=35)	Total (n=196)
<b>Age</b>			
45 or younger	9 (6)	16 (46)	25 (13)
46-65	64 (39)	14 (40)	78 (39)
66-75	54 (35)	2 (6)	56 (29)
76-85	26 (17)	1 (3)	27 (14)
Older than 85	3 (2)	0 (0)	3 (2)
Age not given	4 (3)	2 (6)	6 (3)
<b>Gender</b>			
Male	100 (63)	15 (43)	115 (59)
Female	59 (37)	18 (51)	77 (40)
Gender not specified	2 (1)	2 (6)	4 (2)
<b>Time Since Stroke</b>			
Less than a year	23 (14)	7 (20)	30 (15)
1-3 years	70 (44)	15 (43)	85 (44)
3-5 years	41 (26)	11 (31)	52 (27)
More than 5 years	23 (15)	1 (3)	24 (12)
Time since stroke not given	4 (2)	1 (3)	5 (2)
<b>Area</b>			
Dublin City and County	60 (38)	14 (40)	74 (38)
Other Urban	55 (34)	9 (26)	64 (32)
Rural	43 (27)	10 (29)	53 (27)
Location not specified	3 (1)	2 (6)	5 (2)
<b>Daily Living</b>			
Lives alone	36 (22)	4 (11)	40 (20)
Lives with spouse or family	106 (67)	29 (83)	135 (69)
Independent in ADLs* post-stroke	64 (40)	23 (66)	87 (44)
*ADLs = Activities of Daily Living			

## 3.2 Health Problems and Services

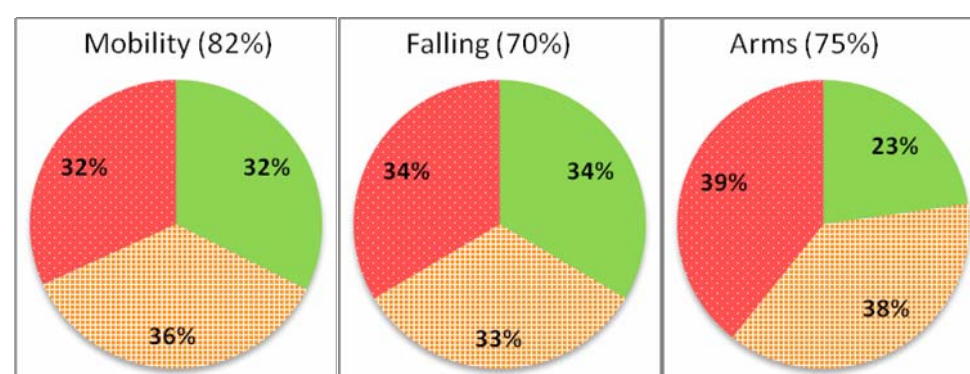
### Stroke-specific problems experienced

Mobility difficulties were reported most commonly, with eighty-three per cent of individuals reporting experiencing this problem after their stroke. Figure 3.2.1 shows how common each problem was among our respondents after their stroke. Emotional problems, fatigue, concentration and arm dysfunction were reported almost as commonly. Problems reported less frequently included difficulties with reading, vision, swallowing, pain and bladder or bowel dysfunction. Approximately half of respondents still reported these problems. Figure 3.2.1 also demonstrates that the majority of respondents wanted help to deal with each problem experienced.



**Figure 3.2.1: How common is each problem**

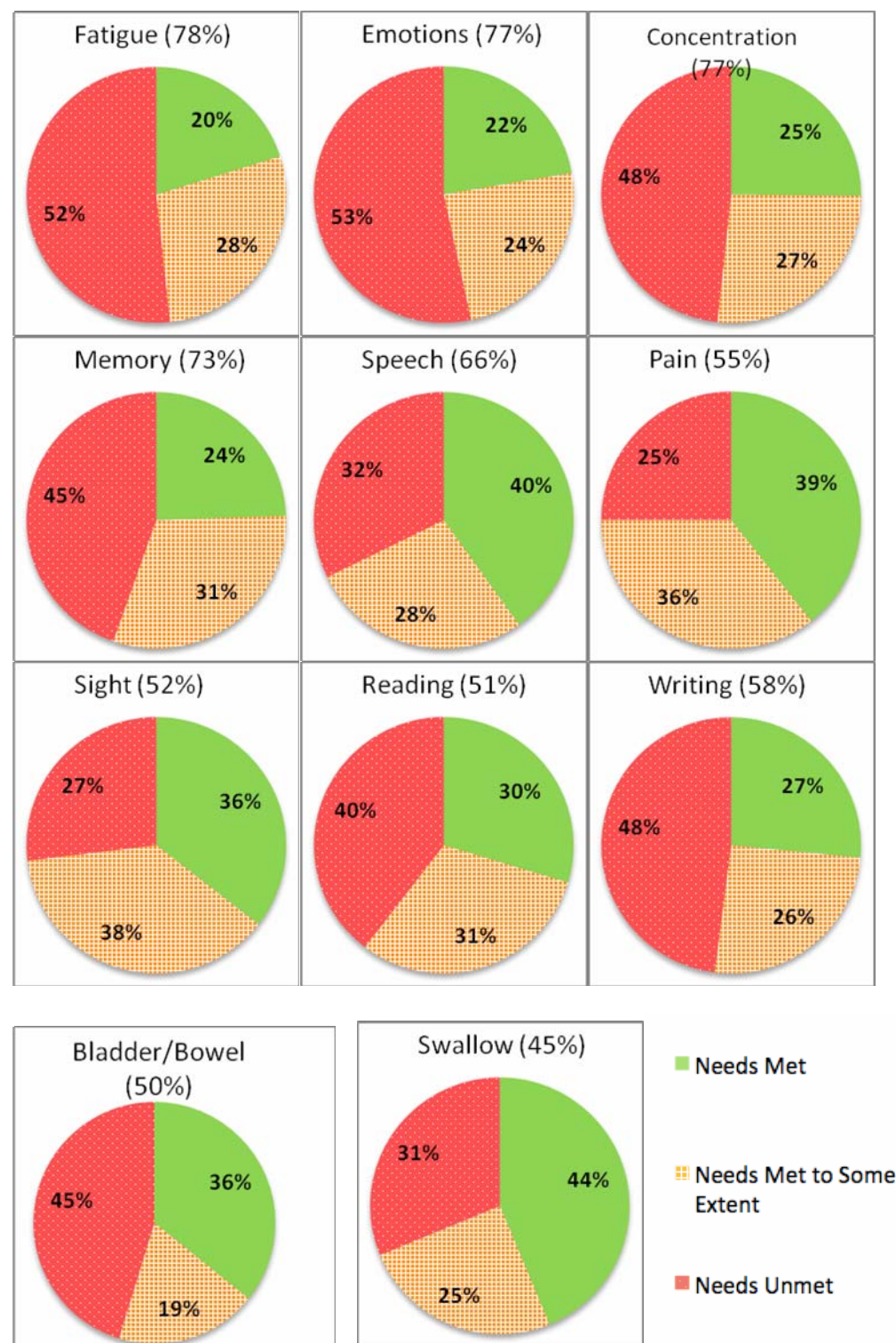
Individuals who reported emotional problems and fatigue also reported poor satisfaction with the level of help they received for these difficulties. Over half of respondents who reported these problems felt they received none or very little treatment for their problem (53% and 51% respectively). Between 40 and 50% of individuals who reported difficulties with writing, concentration, bladder or bowel, memory, and reading felt they did not get enough help. Figure 3.2.2 shows the extent to which different needs were met across reported problems.



■ Needs Met

▨ Needs Met to Some Extent

▨ Needs Unmet



**Figure 3.2.2: Extent to which need is met for different problems. Percentage of respondents who reported experiencing the problem is given for each.**

## Community rehabilitation

The availability of publicly funded community therapy services differed across service type and problems experienced, but not across urban and rural locations, or living situation (i.e. living alone). Table 3.2.1 presents associations between problems reported and community services received.

**Table 3.2.1: Associations between problems reported and services received**

Problems Reported	Community Services Received <sup>176</sup>					
	PT	OT	SLT	Psych	SW	Diet
<b>Mobility</b>	<0.001	0.002	ns	ns*	ns*	ns
<b>Falling</b>	<0.001	<0.001	ns	ns*	0.027	0.003
<b>Arms</b>	<0.001	0.003	ns	ns*	ns	ns
<b>Bladder/ Bowel</b>	ns	ns	ns	ns	ns	ns
<b>Pain</b>	ns	ns	ns	ns	0.015	ns
<b>Fatigue</b>	ns	ns	ns	0.026*	ns	ns
<b>Emotional</b>	ns	ns	ns	0.026*	ns	ns
<b>Concentration</b>	ns	ns	ns	0.025*	0.03	ns
<b>Memory</b>	ns	ns	ns	ns*	ns	ns
<b>Speech</b>	ns	ns	<0.001	ns	ns	ns
<b>Swallow</b>	ns	ns	ns	ns	ns	ns
<b>Reading</b>	ns	ns	<0.001	ns	ns	ns
<b>Writing</b>	0.016	ns	<0.001	ns	ns	ns
<b>Sight</b>	ns	ns	ns	ns	0.045	ns
<b>Dependence in personal care</b>	0.001	0.016	ns	ns	ns	ns

NOTE: The column on the far left represents the problems reported by respondents following their stroke. In this table, we sought to examine if there was a relationship between the problems reported by respondents and the services accessed by them. We considered the relationship as 'significant' if there is a numerical value (p-value) displayed in the box. For example, if we consider mobility as a problem identified by respondents, we can see that there is a 'significant' relationship between the problem (mobility) and the OT and PT services accessed. On the other hand, we would expect that respondents who reported a problem with swallow would have a strong relationship with SLT but this was not the case.

ns = Not Significant

\* Only a small number of respondents reported receiving support from these services

<sup>176</sup> PT=Physiotherapy, OT=Occupational Therapy, SLT= Speech and Language Therapy, Psych= Psychological services, SW= Social Worker, Diet= Dietician



Unsurprisingly, respondents who reported problems with mobility, falling and arm dysfunction were more likely to have received physiotherapy (PT) and occupational therapy (OT) than those who did not report these problems. Similarly, people who reported difficulties with speech, reading and writing were more likely to receive speech and language therapy (SLT). Just over two-thirds of respondents with mobility problems received community physiotherapy and less than half of respondents with relevant problems received community OT or SLT. Table 3.2.2 demonstrates this detail. The association between those with writing difficulties and physiotherapy is confounded by deficits in arm and hand function.

Of the 151 individuals with emotional difficulties only 11% of them received psychological services. Although an association was found between receiving community psychological services and reported fatigue, emotional and concentration difficulties, the numbers who received this service are small. Only 17 individuals (8% of respondents) reported receiving psychological services, with all of them reporting problems with fatigue, emotions and concentration.

In addition, those who attended a community dietician were more likely to report problems with falling, and those who received services from a social worker were more likely to have problems with falling, pain, concentration and sight. These associations must also be interpreted with caution as numbers are small. Only 25 respondents received input from a community dietician while 22 had contact with a community social worker after their stroke. There were no associations found between, memory deficits, swallowing problems or bladder or bowel dysfunction and any particular community services.

The majority of participants who received physiotherapy (PT), occupational therapy (OT) or speech and language therapy (SLT), were able to provide more detail about the amount of treatment they received and the wait for services (79-85% of therapy recipients). Details are presented in Table 3.2.2.

**Table 3.2.2: Details of community services wait times and treatment length**

	No. of respondents (%)					
	<b>PT</b>		<b>OT</b>		<b>SLT</b>	
Received service (% of total)	114	(58)	78	(40)	68	(35)
<b>With selected relevant problems:</b>	(% of those with problem)					
Mobility difficulties	108	(68)	73	(45)	57	(36)
Arm dysfunction	103	(70)	69	(46)	52	(35)
Dependence with personal care	71	(71)	49	(48)	31	(30)
Memory difficulties	79	(56)	54	(37)	52	(36)
Speech difficulties	78	(61)	52	(40)	61	(47)
Swallowing difficulties	49	(60)	37	(44)	33	(40)
<b>Treatment timeframes</b>	(% of those who received service)					
No delay for service	14	(12)	11	(14)	10	(14)
Waited 1-6 months	16	(13)	5	(7)	4	(6)
Waited > 6 months	7	(6)	4	(5)	6	(9)
Treated < 6 weeks	12	(10)	17	(21)	8	(11)
Treated 6 weeks - 6 months	29	(26)	9	(12)	23	(35)
Treated >6 months	34	(30)	27	(35)	17	(26)

When asked if they had any other needs, forty-one respondents said they needed more professional help for specific stroke-related problems. Twenty-one of these re-iterated their need for therapy to improve the physical function of arms and legs. Seven wanted help with communication difficulties and four with swallowing. Three reported a specific need for cognitive rehabilitation. Five want further monitoring and more follow-up from the hospital and therapy services.

“I received all the care initially after my stroke, but since it feels like as a stroke victim the after care about my welfare just stopped”

One person, who lives in a rural area, described poor access to services locally.

“Poor access to community rehab since discharge. Travel 75km each way for rehab services”

Ten people discussed the need for counselling to deal with the emotional aspects of stroke. They feel it was never made available to them.

“I was not told about possible depression and panic attacks. This information should be given to everyone after a stroke”

Help was also required for visual impairment, deafness, dizziness and bladder frequency. Three respondents describe a symptom of general discomfort in their heads made worse by the “constant need to concentrate”.

"I feel a deadness or dullness in the head. To get that sorted would be good. The doctor says I have to live with it"

One individual described wanting health professionals to be more aware of subtle problems, including concentration, after stroke and the implications for returning to work.

Despite frequent reports of delays for services and unmet needs, it is clear that many respondents were grateful for the help that they did receive. When participants were asked what had helped their recovery most since returning home thirty-seven people mentioned the rehabilitation units they attended or specific health care professionals.

“I have had very good follow up from the stroke team in the hospital”

Twenty people specified therapy services including physiotherapy, occupational therapy, and speech and language therapy. Specific interventions that were mentioned included family assisted exercise, and a card to explain dysarthria to strangers. Staffing levels were described to cause some difficulties.

“The OT was brilliant, best thing in the world, I needed her. But she went on maternity leave and I wasn't able to get in touch with any replacement”

Two people felt their GP had helped them the most while two others mentioned their public health nurse. The benefit of psychology was also described.

“the neuro psychologist teaching me ways of coping on a day to day basis”

Five people who attended stroke support groups referred to the group coordinator, who in many cases was a Clinical Nurse Specialist, as the professional who had helped their recovery most since returning home. Seventy-five per cent of our respondents had been to a stroke support group (thirty-four per cent of online respondents and eighty-four per cent of paper respondents). This reflects our method of recruitment. Most paper respondents found it very helpful while most online respondents found it somewhat helpful. When asked to describe what had helped most with their recovery since returning home twenty-two people discussed stroke support groups and fifteen mentioned non-statutory organisations including Headway, Quest and the National Council for the Blind. Benefits of the stroke support groups that were described included increasing self-confidence, social interaction and being a "link for help if needed".

“Headways...have been a great help in my recovery - without them I wouldn't be as good as I am today”

“The stroke support group was my life saver”

## **Private rehabilitation services**

Seventy-one people (36% of respondents) reported paying privately for treatment. The most common private treatment paid for was physiotherapy with thirty people (41% of those who paid for treatment) paying privately for this treatment. Private physiotherapy sessions were described to cost between €30 and €120 each. Thirteen individuals reported paying between €200 and €600 in total on physiotherapy while five respondents have paid in excess of €1000 on physiotherapy since their stroke. Some respondents provided reasons for accessing private services, including long delays and lack of access to publicly funded services.

“I couldn't wait so long for physiotherapy”

“None was available in my area at the time of my stroke”

Seventeen people reported paying private medical costs, with four of them reporting that they have paid several thousand Euros since their stroke. Six respondents have paid for counselling, five for speech and language therapy, five for eye care, one for occupational therapy, and one for a dietician. They report paying between €90 and €1000 in total for these services. Eleven people have paid for adjunctive therapies including acupuncture, hydrotherapy, massage and other alternative treatments. Other significant expenses cited include equipment purchases, ranging from €600 for a leg splint to €4,500 for a wheelchair. When asked what had helped their recovery most since returning home three people mentioned paying for private therapy. One individual described it as “a good investment”.

“Employing a professional speech and language therapist...for six months after my stroke. Her help was great at the time I needed it most - she helped me to remember lots of things I forgot with the stroke”

## **Information Needs**

Most individuals wanted more information about the cause of their stroke (68%), secondary prevention (77%) and their diet (68%). When invited to discuss other needs experienced since their stroke nine respondents detailed different types of information that they would like to receive. Six respondents reported requiring more information about what services and benefits they are entitled to. One respondent felt that a doctor should give this advice a few weeks after the stroke, to highlight the importance of the information. Another respondent describes the difficulty experienced when this information was not provided at discharge.

“I was given no information coming out of hospital, not even phone numbers. I wasn't told what services were available like public health nurse, local clinic, or respite. I found out about everything by hearsay”

Others wanted legal advice, advice for their family members about how best to help them or more information about the effects of stroke.

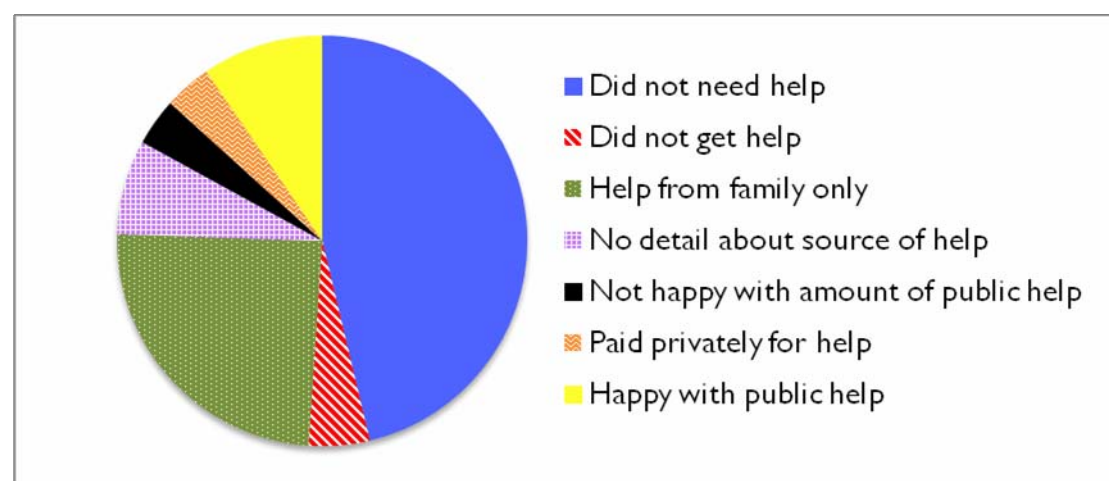
“A bit of education on what way it could affect me would be good, but I suppose it affects everyone differently. It has been a slow learning curve”

### 3.3 Everyday Living

#### Independence in the home

Over half of respondents (52%, 101 individuals) needed help with personal care after their stroke. Nine of these people didn't get the help they needed from any source. Respondents were asked to specify who provided this help, but fourteen individuals did not provide this detail. Forty-six individuals (46% of those who needed help) reported receiving this help from family only. Thirty-one respondents have professional carers, seven of whom pay privately for this service. In addition 7 people with publicly funded carers did not feel they had enough help with personal care. Of all respondents who needed help with personal care after their stroke, 17% received help from the public service and were happy with the level that they received. Figure 3.3.1 demonstrates this detail. One stroke survivor described his particular concerns about this service.

“We need more home help at long weekends or when my wife is sick. There should be provision at local level to provide extra help for short periods.”

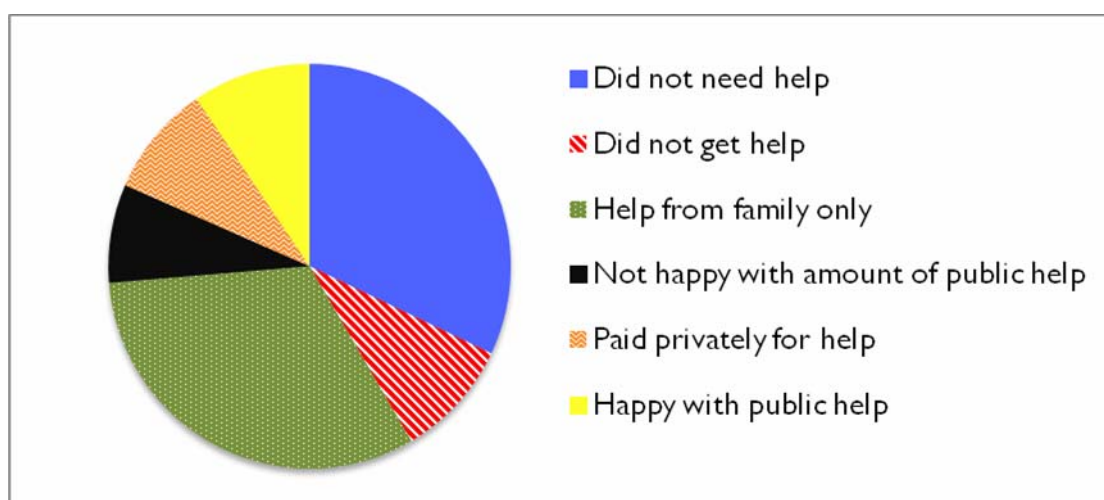


**Figure 3.3.1: Help received for personal care**

Two thirds of respondents (130 individuals) needed help with household tasks, including cooking, cleaning and shopping since their stroke. At least half of them received this help from family members only. Eighteen of those who needed help did not receive it from any source. Seventeen others paid privately for this help. In addition, 10 people feel that they do not receive all the help they need with household tasks. At most, 18 people (14% of those who needed help) received publicly funded home help and were happy with

the level they received. Figure 3.3.2 demonstrates this detail. Five people felt that receiving Home Help was one of the things that had helped their recovery most since returning home. When asked at the end of the questionnaire if they had any other needs seven respondents discussed their need for more help in the home with household tasks and personal care to take some of the burden off their family, or because they struggled with fatigue.

“Would like more help with personal care to enable spouse to work independently”



**Figure 3.3.2: Help received for household tasks**

Thirty per cent of respondents report needing further adaptations inside the home to help them to live more independently. Respondents mainly described bathroom adaptations including installation of a wet room, downstairs toilet and rails in the shower. Also frequently described were stair lifts and handrails. Fifteen per cent of respondents required adaptations to the outside of their home including rails at doors, handrails on external steps and ramps for wheelchair or rollator access.

Thirty-four per cent of respondents had to pay some money towards adapting their home in order to live independently after their stroke. Almost half of these people report that paying for these adaptations affected their finances. Four people report receiving a partial grant. The most common private adaptation described was a stair lift, with eight people installing this privately. Two respondents described the significant affect that home adaptation has had on their finances.

“I had to take out a €5,000 loan to adapt the shower”

“I spent every penny of retirement fund on adapting my home”

Seven people re-iterated their equipment needs at the end of the questionnaire. One respondent discussed the problems with hospital rented equipment.

“I was given an inappropriate wheelchair on discharge and was hounded to give it back. I wasn’t even given any advice about getting another one”

## **Relationships**

Forty-two per cent of respondents who had a partner or spouse at the time of the survey felt that their relationship was significantly affected by their stroke, while a further quarter of respondents feel that their relationship has been somewhat affected. Themes about the nature of this change are discussed below. One person highlighted a positive change in the relationship.

“I know I have a real friend no matter what...”

Four people note that their own personality has changed since the stroke. They report being more short-tempered, argumentative, impatient and difficult to live with.

“I am more impatient and 'difficult' to live with since my stroke and the realisation of my limitations post-stroke”

Two others note that their partners perceive their personalities to have changed but they cannot see the changes themselves.

“She feels that I'm not the man she married since my stroke”

Some respondents noted an increase in tension and arguing, with four people reporting that their relationships have broken down since their stroke.

“Arguing more. Tension constantly dealing with stroke”

For some respondents the physical effects of the stroke, including decreased independence, memory, hearing and balance problems, have made the relationship more difficult or have led to a “role reversal”. Several respondents described how their partners appear to have less confidence in them since their stroke, are overprotective or may be afraid that they will have a second stroke. Difficulty with intimacy was another recurring theme, with some couples afraid to resume a physical relationship. A quarter of respondents who reported being in a relationship wanted information about physical relationships.

“We’re like brother and sister, there’s no intimacy. We’re still close but I guess we’re both afraid...afraid I might have another stroke”

“Problems with body image since stroke affect intimacy”

Respondents described the increased stress, frustration and worries that their partner had since taking on the role of “carer”. Two individuals highlighted

that there is not enough psychological support or advice available for their partner.

Twenty-three per cent of respondents felt that relationships with other family members have changed significantly, while twenty-seven per cent felt they have changed a little. Themes emerging about the nature of this change include understanding, role-change and conversation. Of the 37 people who provided more detail, six people reported a positive change in relationships with family members since their stroke. Some respondents described how family members don't always understand the effects of the stroke, particularly if the problems are invisible. With some respondents there has been a change of roles as they relied more on their family's help or were no longer able to provide the help to others that they used to. Families can also be protective.

"They keep making sure I don't overdo things"

Reasons cited for difficulty participating in conversation with family members included aphasia, decreased confidence, slurred speech, and hearing and memory problems.

"I find it difficult to engage in banter and conversation in groups. My self-confidence has been diminished"

"Some family members don't come near me anymore"

Twenty-nine per cent of respondents feel their relationships with others outside the family have changed significantly, while a third feel they have changed a little bit.

"I had thousands of friends through...(leisure activity)...now I only have five good friends, real friends"

"Friends disappeared after my stroke. I find it difficult to make new friends now"

Although relationship dynamics have changed for many respondents, it was clear that people relied on and appreciated the different types of support provided by family and friends. When invited to say what had helped their recovery most since returning home, 40 per cent of respondents mentioned family and friends. This was by far the most common response. In fact for 20 per cent of respondents, family support was the only thing mentioned.



Twenty-four respondents mentioned their wife, husband, partner, spouse, boyfriend or girlfriend. Most of them referred to appreciating the “help and support” provided but also the “care and attention”, “supportiveness”, “good company”, “emotional support”, “understanding”, “kindness”, “consideration” and “attitude” of their partners. One respondent described her gratitude for the role her husband played in her recovery.

“It was my husband who cooked, cleaned, helped me wash and took me out for little walks to try and get me back on the recovery road”

Participants also referred to help and support provided by immediate and extended family, friends and the wider community. Respondents appreciated the love shown to them as well as other forms of encouragement.

“My daughter nagging me to do it”

### 3.4 Community Activities

#### Transport and driving

Sixty per cent of the respondents who drove prior to their stroke have returned to driving. Forty-three per cent of those who returned to driving required no help. Thirty-eight per cent of them completed a road test while twenty-eight per cent made adaptations to their cars. A quarter of drivers who returned had to receive further training. Several people discussed how the Irish Wheelchair Association had assisted their return to driving. Returned drivers were more likely to live in a rural area and be independent with personal care post stroke. Table 3.4.1 displays the details of the analysis.

**Table 3.4.1: Characteristics of returned drivers**

	<b>Drivers returned</b>	<b>Drivers not returned</b>	<b>p-value</b>
<b>Mean age</b>	59.7 (SD 13.8)	63.8 (SD 13.0)	0.072
<b>Male gender</b>	63%	65%	0.864
<b>Living in rural area*</b>	37%	17%	0.028*
<b>Independent with personal care post stroke*</b>	59%	31%	0.001*
*Difference is significant SD=Standard deviation			

Almost half of respondents who have not yet returned to driving would like information about driving or getting a parking permit, and about transport around the community. Forty-eight per cent of respondents feel their use of transport has definitely changed since their stroke. Not being able to drive anymore is significant for many respondents and is by far the most common reason given for this change.

“It’s totally changed my life and I can’t get used to it”

Some respondents discussed medical reasons and consequences of the stroke that have prevented them from returning to driving. These included visual impairment, hemianopia and seizures. Some individuals have lost confidence in their driving and either do not want to drive or limit their driving to local areas. In many cases a spouse or other family members have been required to assume the role of driver.

“Always depending on family to bring me places. No community transport where I live!”

The second notable theme is the difficulty of transport for wheelchair users. Two individuals were required to adapt their cars to be able to travel in them, and another person described the difficulty of transferring into the car from the wheelchair. One respondent, who described the cost as “prohibitive”, has cited the need for a special taxi as a barrier to attendance at a valued activity. Another individual reported paying €400 a month on taxis.

Other reported reasons for this change included not being able to walk as far, or having difficulties using public transport, which either prevent its use or necessitated supervision. Four individuals highlighted the cognitive demands of travel.

“I was confused, and I was afraid, I get lost, I had problems with memory, so I didn't know in the middle of the trip, where I'm going and what for...”

A further quarter of respondents felt that their use of transport has changed to a certain extent. Themes that emerged about this change include increased caution, need for supervision and avoiding difficult situations while driving, walking or using public transport. Drivers reported having switched to an automatic or adapted vehicle, planning their route in advance, driving less, driving with supervision or avoiding driving at night. Walkers discussed taking longer, being afraid of falling and a general nervousness of people.

“I have to think about where I'm going and if I have to bring a walking stick or if the footpaths are bad”

Users of public transport discussed requiring supervision, the helpfulness of bus drivers, avoiding travelling at rush hour, and using extra caution getting on the bus.

At the end of the questionnaire four people took the opportunity to re-iterate that transport was their most significant need.

## **Leisure activities**

Sixty per cent of respondents felt that their engagement in leisure activities changed significantly after their stroke. Two-thirds of these people provided more detail. While four people described an increase in exercise, sixty responses highlighted the negative impact that the stroke has had on previously enjoyed activities.

“Socially withdrawn and very limited active participation in outside activities”

Respondents described barriers to participation in previously valued leisure activities. Many of these barriers included the direct effects of the stroke: reduced mobility, balance deficits, fatigue, decreased hand function, pain, co-ordination difficulties, aphasia, dysarthria, epilepsy, visual/ hearing impairment, writing difficulties. Psychosocial barriers were also described including fear, lack of self-motivation and loss of interest in activity. Seven people cited transportation as a barrier. Participation in a group or club was also prevented by the concerns of others.

“...the club won't let me go anymore. They phoned .... and said not to come because I'm a danger and might fall on the premises”

Most of the affected leisure activities discussed were physical including, walking, swimming, running, cycling, going to the gym, court sports, golf, bowling, playing pool, horse-riding and dancing. Outdoor activities like gardening and fishing were also frequently mentioned. Physical deficits, balance difficulties and fatigue were cited as the main reasons for activity curtailment. Eighteen respondents described having reduced or stopped attending social gatherings including matches, race meetings, the pub, bridge, bingo and volunteering. Fatigue, transportation issues, aphasia and depression were some reasons given.

“Access to places is a big drawback”

Cooking was another missed activity, with safety concerns about cutting and handling hot objects discussed by three people. Attending plays, watching TV, reading, computer and radio use were affected by hearing and visual impairment, concentration difficulties and arm dysfunction. Nine people expressed a particular need for help with finding new leisure activities or accessing the ones they previously enjoyed.

### **3.5 Work and Finances**

#### **Employment**

At least a third of respondents were retired or working in the home before their stroke. Only 23% of those under the age of 66 reported that they have worked in a full or part-time capacity since their stroke. This compares to at least 56% of them working before their stroke. There were no associations found between returning to employment and reporting specific problems after stroke. Five of the people who returned to work were able to resume their original role without assistance, however one of them reports taking early retirement four months later. Two of the others commented on difficulties caused by residual deficits, and the lack of support for graduated return to work. The remaining 19 individuals that returned to employment have been able to adjust their role or reduce their hours. Four of these people were self-employed, two received training and support and two lost their jobs within a few years of returning.

“Went back but physically couldn’t do the work. Lasted less than a year. Employer didn’t engage.”

Respondents discussed barriers to returning to work in general and to specific roles. Themes that emerged include transport, communication and cognitive problems, fatigue, physical deficits and public perception.

“..only able to work half the hours and not as efficient”

Individuals with decreased strength since their stroke described difficulties returning to physical work including farming, construction and cleaning. There were also safety implications to operating machinery and being around livestock. Individuals with manual skilled or service industry jobs described the barriers of cognitive deficits and hand dysfunction. The ability to perform complex tasks was affected. Computer work was affected by visual impairment and co-ordination problems.

“I have noticed that when I went back to work after my mild stroke, I keep making mistakes on the keyboard of the computer, punching the wrong button”

Other factors associated with returning to work were financial or employer-related. One respondent described the fear of losing disability allowance for an unsuccessful attempt at returning to work. The difficulty of negotiating employer’s requirements was also described.

“I looked into getting back to work but I never got a straight answer from my employer. I had meetings, they wanted a doctor’s note, a physio note and I got those, but they said I wouldn’t be covered by insurance.”

When asked about other needs three people said they would like help getting back to some kind of work or contact from their previous employer.

“Biggest issue is some means of getting part-time work - there is a big gap in 'preparation for work' etc.”

## **Finances**

Almost sixty per cent of respondents report that their finances have been affected by their stroke. Thirty per cent of respondents have experienced either a decrease in income or an increase in expenses while twenty-seven per cent have experienced both a decrease in income and an increase in expenses. Nineteen per cent of all respondents and twenty-eight per cent of those under 66 cannot afford their gas and electricity bills with several more saying they can “just about” afford their bills or are “struggling”. Many respondents noted receiving higher fuel bills.

“Since stroke I feel the cold more/ limited mobility - central heating on for more hours than previously”

Over sixty per cent of the respondents who are under the age of 66 have experienced a decrease in their household income since the stroke, mostly due to changes in employment. In contrast a quarter of respondents over the age of 66 experienced a decrease in income, as most were retired before their stroke. Forty-four per cent of respondents under 66 and thirty per cent of those over 66 experienced an increase in expenses since their stroke. In both groups this was reported to be mainly due to bills, transport costs, the need for home adaptations, medication and rehabilitation services. Almost half of respondents under the age of 66 receive a disability allowance and fifty-six per cent have a medical card. In comparison eighty-two per cent of respondents over the age of 66 receive a pension and sixty-five per cent reported having a medical card. Forty per cent of those over the age of 66 report that financial changes since their stroke has had an impact on their daily lives. This increases to three quarters of respondents under the age of 66. This impact included cutting back on socialising, little luxuries, heating and some essentials. A quarter of respondents worry about their financial future.

‘On a number of occasions I have postponed filling my prescription because we could not afford it’

Thirty-four carers were receiving a carer's allowance at the time of the survey, although nine respondents specified that it is paid at "half rate". Ten per cent of families were receiving the respite grant. Twenty-eight individuals felt that their spouse or family members' work has been affected by their caring role. This has an impact on the household income of ten respondents. Three people reported that their carer has had to leave their job, while ten carers reduced their hours or changed their rota. One person described how their partner now works the night shift so that they...

"can be at home during the day to keep an eye on me and bring me to appointments and meetings"

When asked about other needs at the end of the questionnaire three people re-iterated financial needs, specifically for transport and medications.

"Every stroke survivor should have a medical card"

### **3.6 Open Responses**

#### **Other needs**

Forty-three per cent of respondents took the opportunity to provide an open response about additional needs, to re-iterate important needs discussed previously or to make other comments about their recovery since their stroke. Needs expressed can be categorised into the following themes: physical and cognitive, psychological needs, personal care, equipment, financial needs and help with community re-integration. Many of these needs have already been discussed in detail.

Two respondents highlighted the importance of increasing the public's awareness about the effects of stroke. One of these people discussed how the invisibility of certain problems makes dealing with them harder, as members of the public can get impatient. The other respondent discussed the difficulties of others' perception of aphasia while in hospital.

"Nobody spoke to me at all. Having no speech did not mean I lost my reason, sense of humour and would have appreciated being acknowledged with dignity and humanity."

Two respondents discussed how the fear of recurrent stroke affected their recovery.

"I need to gain the confidence to engage again with the world without the fear of having another stroke"

"Having 'survived' the stroke I live in fear of a second stroke and am gradually accepting the diminution of my faculties and the 'new' me"

## **Facilitators of recovery**

The majority of respondents (91%) took the opportunity to describe what helped their recovery most since returning to live in the community after their stroke. Themes that emerged from these responses include family support, stroke support groups, personal attributes, health professionals, exercise and being at home. Many of these themes have been discussed in detail in previous sections.

As described, 80 respondents mentioned the support of their spouse, family or friends. Thirty-seven respondents detailed health professionals or rehabilitation services. Thirty people discussed stroke support groups or non-statutory organisations.

Thirty-two people discussed personal attributes that had helped their recovery after their stroke. Nine people mentioned “determination”, seven cited a positive attitude while five discussed “motivation”. Similar thoughts were expressed by several other participants who valued their own “get up and go”, willpower, “stubborn personality”, “pride”, and desire to “get back into action”.

“Said to myself “I’m not going to lie in bed- gonna get up and do things”

Participants also felt that personal coping strategies, having a balanced approach, working hard with therapy, and having goals had helped them.

“What helped me was I used to set different goals every week e.g. walking a bit longer. Increase my tasks e.g. housework. Do a little bit every day”

Personal history, for example being single or having a background working in healthcare were seen by some as facilitators to recovery.

Thirteen people felt that “being at home” in their own environment had helped their recovery. It facilitated “getting back to as normal a life as possible”. Eight respondents discussed different forms of exercise including walking, swimming, and those prescribed by their physiotherapist. It was seen as important to get “out and about” and get back to valued activities including driving and work.

“I have maintained a regular programme of exercise, fresh air, worthwhile activities and diet”

Some participants also felt that medication, relaxation, technology or “time” helped their recovery. One respondent also valued the assistance of their local TD.

### 3.7 Comparisons With Other Surveys

Our findings will now be presented for comparison with applicable reported results from the UK Stroke Survivor Needs Survey, the Australian National Stroke Foundation “Walk In Our Shoes” Report and the Irish National Audit of Stroke Care (INASC) National Survey of Community-Dwelling Stroke Patients and Carers.<sup>177</sup> Further details about these surveys are presented in Chapter 1.

The characteristics of our sample are comparable to those in other similar pieces of research. See Table 3.7.1 for details. The gender balance in our study was similar to both the INASC and UK surveys, however a greater proportion of our respondents were under the age of 65. The INASC sample represented those with more recent strokes, with all respondents being between 6 and 36 months post stroke. In comparison, thirty per cent of the UK sample and thirteen per cent of our sample had their strokes more than 5 years ago.<sup>178</sup> Sixty-three per cent of our sample were married and twenty per cent were currently living alone. In comparison fifty-five per cent of the INASC sample were married, and twenty-four per cent were living alone.<sup>179</sup> Minimal information was available about demographic characteristics of the sample of stroke survivors surveyed for the Australian National Stroke Foundation report.<sup>180</sup>

**Table 3.7.1: Comparison across stroke survivor surveys**

	<b>Current study</b>	<b>INASC 2007</b>	<b>UK Needs 2009</b>
% Over 65	45%	52%	70%
% Male	59%	57%	55%
% >5 years since stroke	13%	0%	30%
Response rate	65%	55%	60%
No. of respondents	196	139	571
Source: (Hickey et al., 2008, McKevitt et al., 2010)			

Problems with mobility were commonly reported among our sample. This was found in both the UK and Australia.<sup>181</sup> All problems were reported more commonly in our sample than in the UK, particularly emotional problems, which were reported twice as commonly by our participants.<sup>182</sup> Figure 3.7.1 compares the frequency of reported problems between our sample and the UK study.

<sup>177</sup> McKevitt, et al., 2010, National Stroke Foundation, 2007, Hickey, et al., 2008

<sup>178</sup> Hickey, et al., 2008, McKevitt, et al., 2010

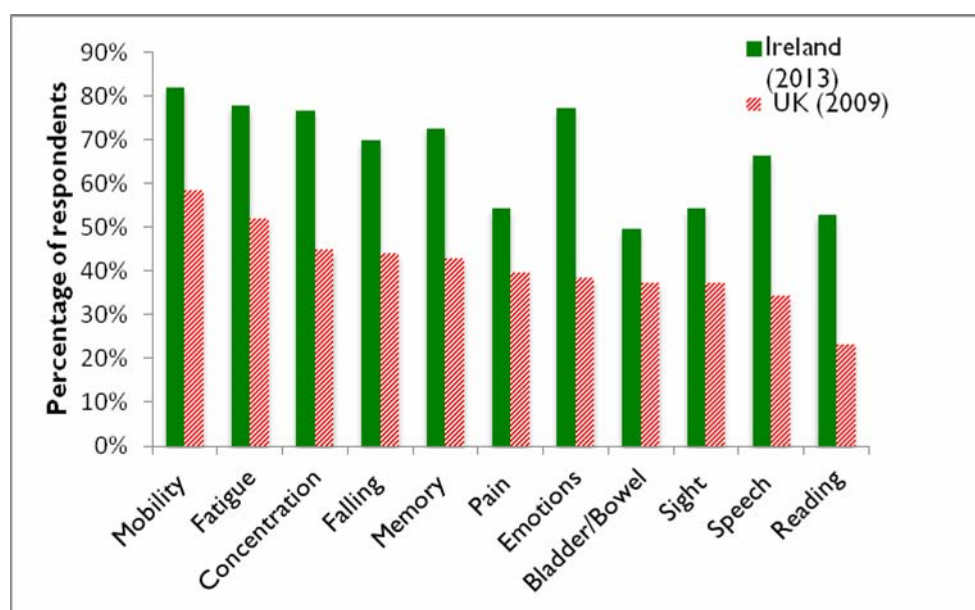
<sup>179</sup> Hickey, et al., 2008

<sup>180</sup> National Stroke Foundation, 2007

<sup>181</sup> McKevitt, et al., 2010, National Stroke Foundation, 2007

<sup>182</sup> McKevitt, et al., 2010





Source: (McKevitt et al., 2010)

**Figure 3.7.1: Comparison of reported problems between samples**

The UK report reflects trends in our results that suggest there is greater satisfaction with help for physical than for cognitive problems. In general our results demonstrate a higher level of unmet need than the UK study across all problems with the exception of memory difficulties. In particular our sample has twice the level of unmet need in relation to bladder and bowel dysfunction.<sup>183</sup> Table 3.7.2 compares levels of met and unmet need across all problems studied in both samples.

**Table 3.7.2. Comparison Between Ireland and UK Needs**

Problem	Needs Unmet		Needs Met To Some Extent		Needs Met	
	Ireland (2013)	UK (2009)	Ireland (2013)	UK (2009)	Ireland (2013)	UK (2009)
Emotions	53%	39%	24%	34%	22%	27%
Fatigue	52%	43%	28%	36%	20%	21%
Concentration	48%	41%	27%	39%	25%	20%
Bladder/ bowel	45%	21%	19%	40%	36%	39%
Memory	45%	59%	31%	25%	24%	16%
Reading	40%	34%	31%	43%	30%	23%
Falling	34%	21%	33%	47%	34%	32%
Speech	32%	28%	28%	39%	40%	33%
Mobility	32%	25%	36%	43%	32%	32%
Sight	27%	26%	38%	35%	36%	39%
Pain	25%	15%	36%	34%	39%	51%

Source: (McKevitt et al., 2010)

<sup>183</sup> McKevitt, et al.,2010

Access and delays for community services reported by our respondents were comparable to the INASC sample. Eighteen per cent of our respondents and twenty-four per cent of their respondents reported receiving no community services. Ten per cent of the INASC sample reported delays of between one and six months in receiving services.<sup>184</sup> Although not all of our respondents provided this detail four per cent of them reported waiting between 1 and 6 months, and a further three per cent reported waiting longer than 6 months.

A significant finding from our results is that only eleven per cent of respondents who reported emotional difficulties received community psychological services. When asked about other needs ten people specifically mentioned counselling to deal with the emotional consequences of stroke and felt it had not been made available to them. In addition, six of our respondents paid privately for counselling. Only one fifth of respondents with emotional difficulties felt they had received enough help. The INASC also found high levels of unmet need among those who reported emotional difficulties. Almost three quarters of their respondents with these difficulties felt they did not get enough help and support after leaving hospital.<sup>184</sup> It must be noted that, as with the UK, the INASC reported only half the levels of emotional difficulty found in our sample.<sup>184</sup> The Australian study reported much higher levels of emotional dysfunction post stroke with two-thirds of their sample reporting periodic recurrences of depression and almost one quarter reporting feeling depressed at least several times a week.<sup>185</sup> Although reported prevalence of emotional difficulty varies across surveys, satisfaction with help for these problems was generally found to be low.

The majority of our respondents wanted more information about the cause of their stroke (68%) secondary prevention (77%) and their diet (68%). This compares to 54% of respondents in the UK survey wanting more information about their stroke, and 37% wanting more information about diet.<sup>186</sup> The INASC report highlighted that there was a lack of information provided at discharge about secondary prevention and the use of medications.<sup>184</sup> Similarly, there was an emphasis in the Australian study on the need for advice about secondary prevention.<sup>185</sup>

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<sup>184</sup> Hickey, et al., 2008

<sup>185</sup> National Stroke Foundation, 2007

<sup>186</sup> McKevitt, et al., 2010

Stroke was reported in our study to have a significant effect on personal relationships. Forty-two per cent of our respondents who had a partner or spouse felt that their relationship was significantly affected by their stroke. This is reflected in findings from the UK and Australia with forty-two per cent and thirty-seven per cent of respondents respectively reporting negative changes in relationships.<sup>187</sup> Feelings of dependency, personality changes, tension and problems with intimacy were described by our respondents as affecting relationships. A quarter of our respondents who had partners wanted advice about physical relationships. This compares to just nine per cent in the UK wanting further information on this topic.<sup>188</sup>

Due to our method of recruitment it is unsurprising that the majority of our respondents reported having attended a stroke support group. In comparison only nine per cent the UK sample had attended a support group.<sup>188</sup> There appears to be differences in the value attached to stroke support groups across countries. During the INASC survey over half of their respondents reported that they would have liked some information in relation to voluntary stroke support groups in their area, but did not receive any.<sup>189</sup> In Australia stroke support groups were rated as valuable by nearly eighty per cent of all stroke survivors.<sup>190</sup> In contrast, in the UK, sixty-one per cent reported that they had not wanted to attend a support group.<sup>188</sup>

Changes in leisure activities and driving status were comparable across surveys. We found that sixty per cent of respondents felt that their engagement in leisure activities changed significantly since their stroke, compared to sixty-two per cent in Australia and sixty-seven per cent in the UK.<sup>187</sup> Sixty per cent of our respondents who drove prior to their stroke had returned to driving, compared to seventy-one per cent of the INASC sample and fifty-four per cent of the Australian sample.<sup>191</sup>

Less than half of our respondents who worked previously returned to any form of employment. This figure may even be as low as one fifth as incomplete data is available. The INASC reported that over eighty per cent of those working changed employment status after their stroke.<sup>189</sup> In the UK over half of all respondents experienced a change in employment while in Australia over half of those who worked had to retire.<sup>187</sup> Overall forty-five per cent of our respondents experienced a decrease in income. This compares to forty-seven per cent in Australia and eighteen per cent in the UK.<sup>187</sup> Stroke appears to have a significant affect on employment across all studied populations.

<sup>187</sup> McKevitt, et al., 2010, National Stroke Foundation, 2007

<sup>188</sup> McKevitt, et al., 2010

<sup>189</sup> Hickey, et al., 2008

<sup>190</sup> National Stroke Foundation, 2007

<sup>191</sup> Hickey, et al., 2008, National Stroke Foundation, 2007

## **4. Discussion: National Survey of Stroke Survivors**

### **Statement of principal findings**

The results of the National Survey presented in this report provide a detailed insight into levels of unmet need among stroke survivors in Ireland. Stroke had a personal, social and economical impact on many of our respondents' lives. Mobility difficulties were the most common problem reported after stroke. Emotional problems, fatigue, concentration and arm dysfunction were reported almost as commonly. Satisfaction with the level of help available for all problems was poor, with between twenty and forty per cent of those with stroke-related difficulties feeling that they had received enough help. Emotional distress and fatigue were common barriers to many activities and satisfaction with help for these problems was particularly low.

Approximately two-thirds of those with physical problems received community physiotherapy, while around half of those with relevant problems received community occupational therapy or speech and language therapy. Psychological, dietician and social work services in the community were available to only a tenth of our respondents.

Family members and spouses provided the majority of help for personal care and household tasks to stroke survivors. In addition they provided much practical and emotional support. Many respondents viewed this support as significant to recovery. Unfortunately stroke was also reported to have a significant affect on personal relationships. Emotional consequences of stroke, changes in personality, levels of dependence, and role reversal were reported as contributors to this.

The social and leisure activities of most respondents were also affected. Reasons for this change included the primary-effects of the stroke, psychosocial barriers, lack of transportation and others' negative perceptions. Moderate levels of return to driving were reported, especially in rural areas where three-quarters of drivers had successfully returned.

Stroke was reported to have had a significant affect on household finances, particularly for those of working age. Increases in expenses were caused mainly by the need to pay for rehabilitation, medication and home adaptations and an increase in fuel and transport costs. Successful return to work levels were particularly low with less than a quarter of respondents of working age having held paid employment in any capacity since their stroke.

## Findings in the context of other studies

As found in the systematic review published in this report, respondents to the national survey perceived the primary effects of stroke to be barriers to community re-integration. Physical deficits, balance and fatigue were cited as the main reasons for curtailment of physical leisure activities. Fatigue and impairment of communication, memory, concentration, vision and physical ability were seen as barriers to returning to work. Reasons for not returning to driving included visual impairment, hemianopia and seizures. Social interaction was affected by aphasia, dysarthria, hearing impairment, fatigue, concentration difficulties and depression.

Although problems with mobility, arm function and falling were frequently reported, satisfaction with level of treatment received for these physical problems appeared to be higher than for cognitive problems. This reflects the findings of the UK Stroke Survivor Needs Survey.<sup>192</sup> Our results suggest that people experienced high levels of fatigue, emotional, memory and concentration problems after their strokes and many did not feel they received the help that they needed. Associations were found as expected among our sample between physical problems, and referral to community physiotherapy and occupational therapy (OT). Interestingly referral to community OT was not associated with any cognitive or perceptual problems (memory, fatigue, concentration, sight), for which OTs can provide assessment and management strategies.<sup>193</sup> This may reflect a greater focus on physical problems by professionals or it may point to difficulties with treatment of cognitive problems.

Emotional challenges emerged from both the systematic review and national survey as significant barriers to community re-integration. Many participants reported depression and anxiety and felt they had not been warned about these symptoms. In contrast positive emotions, including determination and perseverance were seen by respondents as facilitators to recovery. This is supported by findings from the systematic review. Other surveys have demonstrated varying prevalence of emotional problems among stroke survivors. However, in those who report emotional problems there are high levels of dissatisfaction with help and support received across studies.<sup>194</sup> Community psychological services were received by only 17 of our respondents, with 5 of these people paying privately for counselling. The Irish Clinical Stroke Guidelines recommend that stroke survivors and their caregivers should have their individual psychosocial needs reviewed on a regular basis. They suggest that clinical psychologists and social workers

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<sup>192</sup> McKevitt, et al.,2010

<sup>193</sup> Irish Heart Foundation Council on Stroke, 2010

<sup>194</sup> Hickey, et al.,2008, McKevitt, et al.,2010, National Stroke Foundation, 2007

provide counselling and support to address issues including adjustment, impact on relationships, loss and coping.<sup>195</sup>

Families and spouses of stroke survivors were reported to provide high levels of support, for which respondents expressed gratitude. Significant effects on personal relationships were also described, a finding reflected across international surveys.<sup>196</sup> Several respondents described their relationships as being more difficult since their stroke due to decreased independence and changes in roles. Others reported recognising the extra burden on their spouses or families and wanted practical and emotional help to ease this for their loved ones. This theme of “support and dependency” was also identified through the systematic review.

The systematic review also described how a sense of belonging could promote community re-integration after stroke while perceived stigmatisation could have the opposite effect. Several of our respondents reported feeling a lack of understanding from family, friends and strangers, especially in relation to invisible symptoms. In contrast respondents mostly spoke about a sense of belonging when they described their involvement with a stroke support group. Our respondents reported many benefits of the groups including increasing self-confidence, social interaction and being a link for help. Due to our method of recruitment attenders of stroke support groups are over represented in our study.

Rates of return to driving in our sample are comparable to other similar surveys.<sup>197</sup> Among our respondents, returned drivers were more likely to live in a rural area and be independent with personal care post stroke. This suggests that those living in more remote areas were motivated to drive out of necessity. This has community access implications for stroke survivors living in rural areas who are unable to return to driving due to functional deficits or medical complications. Not being able to drive anymore was reported as significant for many respondents. Several participants mentioned lack of transport as a barrier to returning to work or leisure activities. This barrier is also described in the systematic review.

Internationally, return to work after stroke is reported to be poor.<sup>198</sup> This was particularly true among our respondents. Only a quarter of individuals of working age held any employment after their stroke. Detail emerged from our study that suggested that many of those who returned to work were unable to sustain employment, encountered challenges, had to reduce their hours or adjust their roles. This had a significant affect on the household finances of

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<sup>195</sup> Irish Heart Foundation Council on Stroke, 2010

<sup>196</sup> Hickey, et al., 2008, McKevitt, et al., 2010, National Stroke Foundation, 2007

<sup>197</sup> Hickey, et al., 2008, National Stroke Foundation, 2007

<sup>198</sup> Hickey, et al., 2008, McKevitt, et al., 2010, National Stroke Foundation, 2007

respondents, particularly those under the age of 66. In addition, forty per cent of respondents experienced an increase in expenses as described previously.

### **Clinical implications**

It has been highlighted that emotional problems are common post stroke and that satisfaction with help for these problems is low. Furthermore access to psychological services and social workers in the community appears to be poor. Regular reassessment of psychological needs for stroke survivors in the community should be carried out as recommended by the Irish Stroke Clinical Guidelines. Improved access to counselling services could assist stroke survivors to overcome emotional barriers to community re-integration.

Satisfaction with help for cognitive problems including fatigue and concentration difficulties appears to be lower than for physical problems. Community based health care professionals, including occupational therapists, who provide management strategies for these problems should be aware of this finding. General practitioners should also be aware of local community services and organisations that can provide support for these problems so that appropriate referrals can be made.

Levels of successful return to work were found to be particularly low. Barriers at a personal, social, environmental and organisation level have been identified as significant. The Irish Stroke Clinical Guidelines make several recommendations about vocational activities after stroke. These include establishing work history and current goals, liaising with employers, carrying out appropriate assessments and providing specific advice about the process. Health care professionals working with stroke survivors of working age in both acute and community settings should consider these recommendations.

Family members and spouses of stroke survivors provide significant practical and emotional support. They also live with changes to their personal relationships. This study does not investigate the experiences of carers themselves. Further research is needed to establish levels of unmet need among carers of stroke survivors in Ireland.

## **Strengths and weaknesses of the study**

Our sample represents members from 18 stroke support groups and four groups run by non-statutory acquired brain injury organisations. It also represents users of national websites and social networking sites that provide advice and support about stroke and brain injury. It is not a random sample of all individuals who have experienced a stroke in the last five years. For this reason it is likely to exclude both the most isolated stroke survivors, who may have the greatest level of need, and those least affected and not seeking support after their stroke. Comparisons with other surveys suggest that our respondents report higher levels of stroke-related problems. Our sample may have been more severely affected by their strokes, had more emotional consequences or had more awareness of their problems.

Every effort was made to access a sample that was representative of the national geographical spread. In so far as was practical, recruitment was weighted across counties in Ireland according to the Census 2011 population figures.<sup>199</sup> In areas where there was no stroke or brain injury support group, health care professionals acted as gatekeepers and posted questionnaires on our behalf. Response rates in these areas were poor at 40%, in comparison to a 74% response rate from group members. Our sample is representative of the Dublin/ non-Dublin spread. However, it includes more respondents living in urban areas and less in rural areas than in the general population. This may be due to several reasons. The majority of stroke support groups are in towns and cities and so are more easily accessible to those living in urban areas. In addition, unlike the national census our survey contained no standard definition for a “town”, which may have resulted in respondents living in small villages being included in the urban category.

Unfortunately we did not have complete data available in relation to pre-stroke working status. Figures reported therefore give a conservative estimate. Our finding that return to work rates are poor is supported by other similar research. Furthermore, detail provided by participants who did return to work highlights substantial difficulties with resuming paid employment after stroke.

Overall the results of the National Survey provide an insight into levels of unmet need among persons up to five years post stroke in Ireland who are living with residual deficits. They also provide details about barriers and facilitators to community re-integration among stroke survivors. These findings are supported by a systematic review of the literature.

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<sup>199</sup> Central Statistics Office, 2011



## 5. Conclusions

Several problems are reported frequently including mobility difficulties, emotional problems, fatigue, concentration and arm dysfunction.

Emotional distress and fatigue are common and they are significant barriers to many activities. Satisfaction with the level of help available for these problems is poor. There is also minimal access to psychological services in the community.

Personality traits and positive emotions including determination and perseverance were seen as facilitators of recovery.

Stroke had a significant impact on household finances, particularly for younger individuals. Common substantial expenses included private physiotherapy, home adaptation, fuel and medications.

Over half of respondents needed help with personal care and two thirds needed help with household tasks since their stroke. Family provided most of this help. Family support was an important facilitator of recovery. Stroke was also found to have a significant effect on relationships. The level of unmet need among carers requires investigation.

Moderate levels of return to driving and very poor levels of successful return to work were found among the stroke survivors who participated in this study.

Factors associated with community re-integration post stroke include the primary effects of the stroke, emotional barriers, personal perseverance and adaptability, meaningful activities, family support, flexibility of social actors, community access and healthcare professionals.

Professionals and policy makers should particularly recognise the lack of satisfaction with help for psychological and cognitive problems after stroke. More emphasis should also be placed on vocational activities for stroke survivors of working age.

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## **Appendix I: Detailed Methodology of Systematic Review**

### **Study design**

In recent years, there has been a growing recognition that the combination of qualitative data (interviews and focus groups) from individual research studies can produce new insights and conceptual approaches that would not be possible with individual studies alone.<sup>200</sup> For the purposes of this review, a meta-synthesis of studies that examined factors associated with community re-integration in the first year after stroke was conducted. Meta-synthesis is a process of assessment, comparison and interpretation of the findings of published qualitative studies with a focus on increasing the understanding of a specific topic of interest.<sup>201</sup> Although the particular methodology continues to develop, the process of meta-synthesis may facilitate the incorporation of qualitative research findings into evidence based practice. Based on previously published descriptions of process the present meta-synthesis comprised three steps:<sup>202</sup>

1. Identifying relevant papers for inclusion
2. Critical appraisal and data extraction
3. Analysis and synthesis of findings

### **Identifying relevant papers for inclusion**

A systematic literature search was conducted in July 2013 and included the following search engines: PubMed, EMBASE, Cochrane Library, PsychInfo EBSCO, CINAHL and SCOPUS. A combination of the following keywords and MeSH terms were used: "stroke" OR "cerebrovascular disorders" OR "haemorrhage" AND "re-integration" OR "reengagement" OR "engagement" OR "integration" OR "participation". The search was supplemented by hand searching reference lists of retrieved articles.

Studies were limited to those published since the year 2000 as older research of this nature would not reflect current factors associated with community re-integration in the first year after stroke. We only included studies where  $\geq 80\%$  of participants completed their first interview in the first 12 months after stroke. Articles were also limited to those published in the English language only. This methodology is in keeping with previous research of this kind.<sup>203</sup>

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<sup>200</sup> Reed, et al., 2012, Salter, et al., 2008

<sup>201</sup> Salter, et al., 2008, Bondas and Hall, 2007

<sup>202</sup> Bondas and Hall, 2007, Campbell, et al., 2003

<sup>203</sup> Reed, et al., 2012

To determine initial suitability for inclusion in the appraisal and synthesis process, two screening questions were applied to each article:<sup>204</sup>

- Does the paper report findings of qualitative research involving both qualitative methods of data collection and analysis?
- Is the focus of the research paper relevant to the synthesis topic?

Studies that used a mixed methods approach (i.e. a qualitative component used to supplement a quantitative study), where the primary focus of the study was quantitative were excluded.

Papers were considered for inclusion only if they reported the use of established qualitative methods to explore factors associated with community re-integration after stroke from the perspective of individuals with stroke. Studies that focused on community re-integration after stroke from the perspective of the caregiver, family, or healthcare professional were excluded. In addition, studies that explored related topics such as interventions to improve re-integration and processes or goals for recovery and rehabilitation were excluded.

### ***PubMed Search String***

1. "stroke"[MeSH Terms] OR "stroke"[ALL Fields]
2. "cerebrovascular disorders"[MeSH Terms] OR "cerebrovascular disorders"[ALL Fields]
3. "cerebrovascular"[All Fields] AND "disorders"[All Fields]
4. "haemorrhage"[All Fields] OR "haemorrhage"[MeSH Terms]
5. "haemorrhage"[MeSH Terms] "haemorrhage"[All Fields]
6. #1 OR #2 OR #3 OR #4 OR #5
7. "re-integration" [All Fields] OR "reintegration" [MeSH Terms]
8. "reengagement" [All Fields] OR "reengagement" [MeSH Terms]
9. "engagement" [All Fields] OR "engagement" [MeSH Terms]
10. "integration"[All Fields] OR "integration"[MeSH Terms]
11. "participation"[All Fields]OR "participation"[MeSH Terms]
12. #7 OR #8 OR #9 OR #10 OR #11
13. #6 AND #12

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<sup>204</sup> Salter, et al., 2008



## **Critical appraisal and data extraction**

Currently there are no commonly agreed criteria or checklist of elements with which to assess the credibility and rigour of qualitative research. In fact, the use of a checklist approach to critical appraisal within qualitative research remains controversial and is likely to be an area of continuing disagreement and differing practice.<sup>205</sup> We assessed the methodological quality of included papers using criteria based on the ten questions derived by the Critical Appraisal Skills Programme (CASP).<sup>206</sup> Two researchers (RG and MW) conducted the critical appraisal of study quality. Results of the appraisal of each study were discussed and discrepancies resolved by consensus. In addition, the following information was extracted from each article: number and description of participants, format and setting for data collection, and type of analysis reported. A summary of the original findings, themes, issues, concepts and interpretations was created for each of the selected papers. These summaries were created based on the information contained in the individual appraisal sheets and also by reference back to the original papers, to check details and terminology.

## **Analysis and synthesis of findings**

The synthesis of qualitative research has been described as the marrying of findings on a selected topic based on published findings rather than individual patient data.<sup>207</sup> For the purposes of this review, we used a descriptive meta-synthesis similar to Salter and colleagues, in which unchanged texts of published studies formed the data for analysis and these findings were not deconstructed prior to synthesis.<sup>208</sup> Two researchers (RG and MW) independently reviewed the summaries of identified themes, key issues, concepts and interpretations from each study. Following a review of the main concepts to emerge from each study, a list was compiled and systematic search was undertaken for the presence or absence of these concepts in all the papers to be synthesised.

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<sup>205</sup> Reed, et al., 2012, Salter, et al., 2008

<sup>206</sup> Critical Appraisal Skills Programme, 2011

<sup>207</sup> Salter, et al., 2008, Campbell, et al., 2003, Hammel, et al., 2006

<sup>208</sup> Salter, et al., 2008, Hammel, et al., 2006

**Table A1.1: Detailed quality assessment of included studies**

Authors	CASP Questionnaire									
	1	2	3	4	5	6	7	8	9	10
<b>Alaszewski, et al., 2007</b>	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Unclear† ††
<b>Barnsley et al., 2012</b>	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Clear
<b>Burton et al., 2000</b>	Yes	Yes	Yes	Unclear* **	Yes*	Unclear	Yes	Yes	Yes	Clear
<b>Carlsson et al., 2009</b>	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Clear
<b>Dickson et al., 2008</b>	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Clear
<b>Ellis-Hill et al., 2009</b>	Yes	Yes	Unclear	Yes	Unclear	Unclear	Yes	Yes	Yes	Clear ***
<b>Erikson et al., 2010a</b>	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Clear
<b>Erikson et al., 2010b</b>	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Clear
<b>Gustafsson and Bootle 2013</b>	Yes	Yes	Unclear †	Yes	Yes	Unclear	Yes	Yes	Yes	Clear
<b>Jones et al., 2008</b>	Yes	Yes	Yes	Yes	Yes*	Unclear	Unclear* *	Yes	Yes	Clear
<b>Kubina et al., 2013</b>	Yes	Yes	Yes	Yes	Yes*	Unclear	Unclear* *	Yes	Yes	Clear
<b>O'Sullivan and Chard., 2010</b>	Yes	Yes	Yes	Yes	Yes*	Yes	Yes	Yes	Yes	Clear
<b>Rittman et al., 2007</b>	Yes	Yes	Unclear †	Yes	Unclear	Unclear	Yes	Unclear	Yes	Clear
<b>Robison et al., 2009</b>	Yes	Yes	Unclear †	Yes	Unclear*	Unclear	Unclear* *	Yes	Yes	Clear
<b>Rochette et al., 2007</b>	Yes	Yes	Yes	Yes	Yes*	Unclear	Yes	Yes	Yes††	Clear
<b>White et al., 2012a</b>	Yes	Yes	Unclear †	Yes	Yes	Unclear	Yes	Yes	Yes	Clear
<b>White et al., 2012b</b>	Yes	Yes	Unclear †	Yes	Yes	Unclear	Unclear* *	Yes	Yes	Clear
<b>Wood et al., 2010</b>	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Clear

**Table A1.1 (continued): Detailed quality assessment of included studies**

Details of quality assessment		CASP Key
*	Theoretical saturation not discussed	<b>CASP Key:</b> 1. Was there a clear statement of the aims of the research? 2. Is a qualitative methodology appropriate? 3. Was the research design appropriate to address the aims of research? 4. Was the recruitment strategy appropriate to the aims of the research? 5. Was the data collected in a way that addressed the research issue? 6. Has the relationship between researcher and participants been adequately considered? 7. Have ethical issues been taken into consideration? 8. Was the data analysis sufficiently rigorous? 9. Is there a clear statement of findings? 10. How valuable is the research?
**	Did not explicitly discuss informed consent	
***	Inclusion and exclusion criteria not fully discussed	
****	Did not reference further research	
†	No justification of methodology	
††	But not enough discussion around contradictory evidence	
†††	Discussion contains only summary	

**Table A1.2: Detailed process of thematic analysis**

Category Subthemes	Examples from primary studies
<b>Primary Effects of Stroke</b>	<p>"Visits into the community appeared to be limited by... mobility"(Gustafsson and Bootle); "poor mobility, loss of leg and/or hand function, poor standing tolerance and fatigue, as a reason for their inability to re-engage in active leisure activities"(O'Sullivan and Chard); "difficulties in using a hand, fatigue, speech or memory problems...are a barrier to work"(Alaszewski et al.); "experiences of fatigue... limited their ability to resume previously valued activities"(White et al. a); "For some, the reduction was related to mobility problems"(Rochette et al.); "lost the capacity to perform functions that were fundamental to the tasks involved"(Robison et al.); "Fatigue was also an important factor"(Robison et al.); "main reasons expressed by participants for the lack of re-engagement in leisure activities was the experience of feeling weak, tired and exhausted"(O'Sullivan and Chard); "Many participants with low community integration report having fallen during their first month home"(Rittman et al.); "Fatigue and decreased physical strength were also major concerns"(Rittman et al.); "Severe disability undoubtedly creates a major barrier to return to work"(Alaszewski et al.); "frequent, on-going communication difficulties ...irrespective of the severity of dysarthria"(Dickson et al.); "High community integration, however, did not always coincide with high levels of motor functioning"(Rittman et al.); "uncertainty...related ...to the fluctuations in their ability in everyday life"(Carlsson et al.); "This uncertainty about the level of fatigue...on any given day was a significant barrier to planning ahead for social interaction"(White et al. a).</p>

**Table A1.2: Detailed process of thematic analysis (continued)**

<p><b>Personal Factors</b></p> <p>Perseverance</p>	<p>“Greater expectations of recovery positively influenced how participants felt about outdoor travel”(Barnsley et al.); “Some expected further progress and struggled hard to achieve recovery...others believed they had reached their maximum level of ability and tried to adapt to that level of performance”(Carlsson et al.); Being...an optimistic person, a stubborn person or a very competitive person are the reasons the respondents gave for how and why they tried to cope with their new life situation as they did”(Carlsson et al.); “merits of traits they perceived in themselves such as optimism, determination and perseverance”(Robison et al.); “persevere through the symptoms of fatigue in order to maintain participation in valued roles”(White et al. a); “Personal attitudes associated with improvements included taking the initiative to improve their speech, being determined and practicing”(Dickson et al.); “individuals who had developed a strong sense of their own resilience, even their own indestructibility, tended to treat their stroke as another challenge they could and would deal with”(Alaszewski et al.); “success in achieving an intended goal through their personal perseverance”(Jones et al.); “optimism...was now helping them face the difficulty of adjusting to life after their stroke”(Jones et al.); “Hope appeared to be a major feature of emotional recovery in the first few weeks”(Burton); “others remain optimistic and hopeful for their recovery and make plans to travel and visit family and friends”(Rittman et al.); “(they) exercise because they believe that pushing themselves physically will optimize their recovery”(Rittman et al.); “There was a cyclical relationship between incremental risk taking in activities and success, hope for full recovery and further risk taking”(Kubina et al.); “When participants had low expectations of a prompt recovery, they often avoided pre-stroke activities”(Barnsley et al.); “Previous experience of serious illness and disability which had resulted in early retirement or incapacity benefit acted as a major barrier to working”(Alaszewski et al.); “Survivors who experience low community integration express an outlook on life that consists of taking things easy, hoping they will improve physically as time goes by, eventually being able to return to important activities”(Rittman et al.).</p>
<p>Emotional Challenges</p>	<p>“Some participants limited their engagement in previously valued activities because of the way they felt about their disability and appearance rather than because of physical limitations”(Robison et al., 2009); “Thus people were limited by the fact that they had lost confidence in their bodies and felt uncomfortable by the sensations experienced even though they could achieve the activity”(Robison et al., 2009); “Fear of falling out of doors was a strong barrier for some people”(Robison et al., 2009); “People categorized as anxious were more likely to sit at the hesitant end of the continuum, whereas people not categorised in this way felt more confident about going out into the community”(Barnsley et al.); “being able to rely upon their abilities and having a conception of themselves as a capable person were important issues in their coping efforts”(Carlsson et al.); “Establishing independence required participants to transition from feeling overwhelmed to gaining control”(Wood et al.); “Visits into the community appeared to be limited by reduced confidence”(Gustafsson and Bootle); “when participants reached the stage where they did resume driving, participation in this valued role was challenged by a lack of confidence”(White et al. b); “Several participants with low community</p>

	<p>integration describe becoming emotionally overwhelmed by their limitations”(Rittman et al., 2007); “The decline in participation in active, outside community and leisure activities is often attributed to physical and psychological barriers, including fear of falling, being afraid to leave the house”(Rittman et al., 2007); “many participants described changes in how their voice sounded which also had a negative impact on self-identity”(Dickson et al.); “All informants recounted a sense of being unable to prepare for their stroke, and that the suddenness and unexpected nature of their illness had prevented them from coping better”(Burton).</p>
<p>Meaning Attached to Activities</p>	<p>“People who walked regularly pre-stroke were more enthusiastic about resuming their walking habit and more inclined to challenge themselves than those who did not walk previously”(Barnsley et al.); “Returning home...was the primary source of motivation”(Wood et al.); “desire to return home...had acted as spur to regain independence”(Jones et al.); “Meaningful leisure activities were seen as an antidote to the sorrow they felt and a good way to relearn abilities affected by the stroke”(Carlsson et al.); “People who had meaningful destinations were more likely to travel outdoors”(Barnsley et al.); “People...highlighted a basic need for occupation”(Robison et al.); “Some activities previously enjoyed no longer appeared to give them pleasure...even when specific activities had been re-mastered, the social meaning of those activities appeared to be missing”(Burton); “Individuals who made a rapid return to work clearly articulated the benefits of work and the importance of work in their lives”(Alaszewski et al.); “Meaningful roles, activities and relationships were fundamental to finding fulfilment and enjoyment in daily living”(Wood et al.); “Both the workplace and the home were familiar places where the meanings participants gave to activities inspired and challenged them to engage more fully in their rehabilitation process”(Erikson et al. b); “For some of participants the potential loss of income was an important motivator for returning to work”(Alaszewski et al.); “when considering employment, people appeared motivated by the need to support themselves financially”(Robison et al.); “remaining active in community life and doing the same community activities they did before the stroke was a very important aspect to their recovery”(Rittman et al.); “These individuals perceived stress as a causative factor in stroke and that work caused stress. Such perceptions could act as a barrier to return to work”(Alaszewski et al.); “motivation to make changes to promote their health in order to avoid a new stroke”(Carlsson et al.); “a reduction in the intensity at which that social role was accomplished...as a strategy to avoid excessive fatigue in order to prevent another stroke”(Rochette et al.); “associate their sleeping difficulties partly with the anxiety they felt about having another stroke”(Rochette et al.); “came to value his health, which he believed he had previously ignored over career goals”(Kubina et al.); ““Why did I have the stroke?” and “Will I have another one?” For some people this lack of knowledge led to living a life affected by uncertainty”(Ellis-Hill et al.).</p>

Adaptability of the Individual	<p>“The ability to prioritize on-going participation in valued activities over the longer term was dependent on how participants managed their symptoms”(White et al. a); “actual adaptation in discrete physical activities was not of prime importance, rather it was the ability to cope with physical limitations”(Burton); “learning to accept help enabled participants to engage in activities they enjoyed and to participate socially”(Wood et al.); “many participants learned to effectively manage the issues surrounding loss of independence by accepting help from others”(White et al. b); “...being in charge seemed to provide both press and support for re-engagement in valued activities”(Kubina et al.); “Creating balance between capacity, self-identity and personal expectations was the ultimate challenge of community reintegration”(Wood et al.); “Participants who were able to come to terms with and adapt to their new capacity used strategies such as accepting help and taking one day at a time, adjusting their personal expectations”(Wood et al.); “despite living with significant impairment, some people were able to resume a favoured pastime and take pleasure from it by being a little inventive, accepting help, scaling down the scope of the activity or tolerating lesser performance”(Robison et al.); “they adapted to these limitations when they went out into public places by using assistive devices”(Rittman et al.); “Participants with greater insight into their abilities and limitations appeared more able to effectively problem solve barriers in order to accomplish a desired task”(White et al. a); “Altered expectations appeared to assist participants accept their altered lifestyle and stop “battling” themselves”(White et al. a); “adaptations that might have been previously thought of as unacceptable, became acceptable, or became necessary to keeping that activity in one’s life”(Kubina et al.); “some people were using technology to compensate for restricted mobility”(Robison et al.); “Some participants developed innovative strategies for minimizing such difficulties”(Dickson et al.); “people found different ways to address or mediate the impact of the environmental barriers”(Robison et al.); “As participants assented to their inability to drive, they reframed its implication in a positive way and looked for solutions”(White et al. b); “Participants managed their lack of confidence by adjusting expectations of their abilities and placing self-imposed restrictions on their driving”(White et al. b); “Being unable to fulfil their own expectations was frustrating and reduced motivation to participate socially or in physical activity”(Wood et al.); “The ability to re-evaluate and find new values and goals in life was seen as an important strategy when giving up earlier pursuits was the only option”(Carlsson et al.); “As a further sign of an adaptable outlook, some interviewees identified new activities undertaken or planned as substitutes for pre-stroke activities”(Robison et al.); “Some participants discussed new leisure opportunities and new leisure activities, such as bingo, substituted for past leisure activities”(O’Sullivan and Chard); “These older individuals attributed their stroke and resultant speech difficulties to ageing and consequently ‘accepted’ their level of recovery and speech capabilities”(Dickson et al.); “Attributing physical effects of the stroke to a function of age allows stroke survivors to normalize stroke-related physical changes, ameliorating or muting altogether the effects of bodily changes on one’s sense of self”(Rittman et al.).</p>
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<p><b>Social Factors</b></p> <p>Sense of Belonging versus Perceived Stigmatisation</p>	<p>“A special issue mentioned by the respondents concerning their interaction with others was that their symptoms were in part hidden or difficult for others to see and understand”(Carlsson et al.);“resistant because bus drivers and other passengers did not understand their disabilities”(Barnsley et al.); “Participants also expressed feelings of social stigma”(Rittman et al.). “Some participants felt they were now treated differently and experienced discomfort at being accorded sympathy”(Dickson et al.); “Interactions with strangers evoked a particularly strong emotional reaction”(Dickson et al.); “participants who appeared to have recovered but had on-going limitations due to fatigue and experienced stigmatization from the broader community”(White et al. a); “doing something with someone that matters supported the participants’ sense of belonging and, thus, integration into social worlds”(Erikson et al. a);“Belonging was characterized as feeling part of a group and valuing engagement in its activities. The result was motivation to continue to take part in the group’s activities”(Kubina et al.); “participants’ accounts also highlight the importance of flexibility on the part of significant others in the social context of the activity”(Robison et al.); “church was identified as a major source of social interactions”(Rittman et al.); “Those participants who felt that work colleagues or managers were not supportive and did not recognize and support them, found return to work difficult” (Alaszewski et al.); “Over the year of rehabilitation, the participants felt an easing into belonging that was supported by others both at home and at the workplace”(Erikson et al. a);“the importance of flexibility in relation to working hours and workload and the merits of being able to arrange a phased return, factors, which typically rely on the willingness and cooperation of others”(Robison et al.).</p>
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<p>Support and Dependency</p>	<p>“The assistance received from family and friends was positive and considered integral to the client’s ability to remain at home”(Gustafsson and Bootle); “Their ability to maintain interaction with the community often involved support from others”(Rittman et al.); “Without the support of their families, they would likely not be able to live at home”(Rittman et al.); “All five participants expressed the need for support to ensure that they re-engaged in their leisure activities”(O’Sullivan and Chard); “family and friends supported them...through helping to organize attendance and transportation, introducing the participants to new equipment and techniques that could facilitate the activity and gently promoting continuation with the activity when participants were feeling low or discouraged”(Kubina et al.); “People in the sphere of influence positively influenced outdoor travel if practical support was available”(Barnsley et al.); “The respondents said it was important to protect the family from the consequences of the stroke” (Carlsson et al.); “Families could also be anxious about safety and set rules” (Barnsley et al.); “caused tension between couples”(Dickson et al.);“Feelings of needing help and direction to perform mundane tasks, such as dressing and sitting, provoked negative reactions in all informants”(Burton); “Visits into the community appeared to be limited by.....the need to rely on the assistance of others to drive and assist with walking or wheeling in the community”(Gustafsson and Bootle); “Coupled with this issue of dependency was the availability of others and the need to adhere to other people’s timetables”(O’Sullivan and Chard); “Waiting appeared to be a key feature of this isolation; waiting for help, waiting for family and friends to come”(Burton); “Perceiving the burden of caregiving on their relatives burden, without being able to change the situation, the participants described how the stress of their new situation after the stroke disrupted their social world” (Erikson et al. a); “Participants with smaller social networks often felt like a burden to others, had low motivation and fewer opportunities to engage in meaningful activity”(Wood et al.); “choice to engage in a particular valued activity at a specific time was made with the potential burden for the spouse in mind”(Kubina et al.); “Sometimes the perception of dependency, especially with a deeply personal task such as going to the toilet, acted as a spur”(Jones et al.); “Meaningful activity also provided participants opportunities to give back, particularly to those they cared for”(Wood et al.); “Unable to reciprocate, it was not easy for the participants to feel that they belonged to their old social world”(Erikson et al. a); “Doing things for others was associated with motivation to continue to do self-identifying activities despite a fair degree of challenge”(Kubina et al.); “Connected participants reported contributing to their environment in different ways”(Rittman et al.).</p>
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<p>Environmental Factors</p>	<p>“Many participants did not consider public transport feasible due to their limitations in mobility as they were unable to manage the additional walking distances required to get to and from collection points”(White et al. b); “Driving was seen, even by those who had not returned to it, as key for many aspects of everyday”(Robison et al.); “mobility; for getting to work, shopping and for access to leisure and social activities”(White et al. b); “Driving facilitated the return to valued roles and was associated with optimism at the opportunity to resume” (White et al. b); “Four of the five participants discussed the issue of resuming driving and driving as a key to return to independence post-stroke.”(O’Sullivan and Chard); “Driving was frequently related to independence”(Wood et al.); “For those that did resume driving during the first year post rehabilitation, it was critical to regaining control and independence”(Wood et al.); “changes to how people engaged in activities outside of the home largely due to limited community access.”(Gustafsson and Bootle); “practical issues ...the limitations of not having transport to assist with follow-up appointments”(Gustafsson and Bootle); “The ability to drive was an important difference between those with moderate and those with high community integration”(Rittman et al.); “The decline in participation in active, outside community and leisure activities is often attributed to physical and psychological barriers, including ....transportation difficulties”(Rittman et al.); “Needing to negotiate steep stairs and find a seat quickly were identified by 11 participants as a reason to not use buses”(Barnsley et al.); “The cost of the on-road assessment was also a disincentive”(Barnsley et al.); “the test to recommence driving, especially as they lived in quiet rural areas and were tested in the busy city environment” (O’Sullivan and Chard); “For others, it was mainly caused by an environmental constraint such as with travelling and the inability to get insurance because of the stroke diagnosis”(Rochette et al.).</p>
<p><b>Professionals</b></p> <p>“Being supported versus being abandoned</p>	<p>“most people perceived that this early therapeutic support had helped them”(Robison et al.); “Other participants described the motivation and encouragement provided by therapists”(Jones et al.); “Some had experienced skilled stroke care and rehabilitation that they thought had positively affected their coping process”(Carlsson et al.); “particular importance was placed on the physical exercise that occurred within the rehabilitation gym”(Gustafsson and Bootle); “With respect to community-based services, the clients spoke about receiving follow-up medical appointments, continuing therapy, community services, and home modifications and equipment which were all considered valuable”(Gustafsson and Bootle); “therapy helped to facilitate progress was by responding to problems and solving each difficulty as it arose”(Jones et al.); “physiotherapists’ role in helping them maintain momentum and get on with their lives” (Ellis-Hill et al.); “SLTs...contributed most productively to improvements in speech and support”(Dickson et al.); “visits from health care providers were also overwhelming”(Wood et al.); “losing momentum was a consequence of delays and discontinuity of therapy”(Ellis-Hill et al.); “problems getting the right diagnosis, a lack of understanding of their symptoms, not being admitted to hospital the first time they tried, being discharged too early or not receiving rehabilitation”(Carlsson et al.).</p>

<p>“Being in the picture versus being in the dark Advice</p>	<p>“Several participants took the advice of health professionals quite literally”(Barnsley et al.); “Only one study participant received professional support aimed at enabling a return to work”(Robison et al.);“there were some practical issues raised by others who did not know who to contact”(Gustafsson and Bootle); “inconsistencies and confusion surrounding return to driving processes”(White et al. b); “no one received advice or training for use of transport alternatives or knew about disabled transport options”(White et al. b); “People often felt in the dark about how to manage their physical recovery”(Ellis-Hill et al.); “The time taken to adjust to fatigue was influenced by the knowledge or lack of knowledge about how to deal with the symptoms”(White et al. a).</p>
<p>“Rehabilitation setting creates uncertainty”</p>	<p>“the failure of physiotherapy to engage effectively with their desire to resume previously valued activities is evident”(Robison et al.); “They described feeling controlled by the therapists regarding which direction therapy would take and the activities which were to be practiced”(Jones et al.); “Some reported that professional input was artificial, where the context of therapeutic activity that was designed to help them undertake specific activities bore little resemblance to their own home environments”(Burton); “On coming home the familiar environment becomes unfamiliar and presents many obstacles and so the sense of momentum built up in hospital was seen to be challenged and reduced”(Ellis-Hill et al.); “the participants described how some activities at the rehabilitation clinic neither bore relation to their actual pre-stroke work tasks nor were challenging enough to match the complexity of tasks they needed to return to work”(Erikson et al. b); “considered important to have the opportunity to practice functional activities with the support of the hospital staff both in the hospital and their own environments”(Gustafsson and Bootle);“participants described their new situation after stroke as not being recognized”(Erikson et al. a).</p>

## **Appendix 2: Detailed Methodology of National Survey**

### **Sampling and recruitment**

Participants for the survey were stroke survivors primarily recruited through the Volunteer Stroke Scheme (VSS) clubs and the Irish Heart Foundation's National Stroke Support Group Network. In regions that do not have an active stroke support group the Clinical Nurse Specialist for Stroke, and other Community Health Care Professionals in the area was contacted and asked to invite eligible individuals to participate. Additional participants were recruited through non-statutory organisations that provide services to individuals with acquired brain injury. These organisations include Headway Ireland and Brí, Independent brain injury support and advocacy. The survey was advertised online through the Irish Heart Foundation Stroke website ([www.stroke.ie](http://www.stroke.ie)) and the Headway Ireland website ([www.headway.ie](http://www.headway.ie)), and social networking sites of both organisations. Every effort was made to recruit a number of participants from each geographical location in Ireland to reflect population ratios in the country.

The Irish Heart Foundation National Stroke Support Group Network has links with groups in the Dublin areas of Castleknock, Crumlin, Taney, Whitehall and Tallaght and nationally in Cork city, North Cork County, Kerry, Galway, Ballinasloe, Mayo, Sligo, Wexford, Waterford, Limerick, Tipperary, County Wicklow, Bray and Naas. Each support group has roughly 10-30 active members.

Clinical Nurse Specialists and Community Health Care Professionals assisted with recruitment in the absence of Stroke Support Groups in other areas.

Headway Ireland provides support and services to people affected by brain injury including stroke in the community. They focus on community re-integration and have services in Dublin, Cork, Limerick, Kerry and the South East. Brí, Independent brain injury support and advocacy, is an organisation that provides support, information and advocacy to people with brain injuries, their families and carers. Some of their members have experienced a stroke. Brí holds support groups in Cork, Dublin, Donegal, Kerry, Kilkenny, Longford, Louth, Mayo, Meath, Monaghan, Offaly, Roscommon, Waterford and Wexford.

### ***Inclusion criteria***

Volunteers were invited to participate if they were

- Over 18 years of age
- Had a stroke up to 5 years ago
- Were able to give informed consent
- Were able to communicate
- Had an Abbreviated Mental Test Score of >6
- Were living in their own home within the community

### ***Exclusion criteria***

Volunteers were excluded if

- They were less than 18 years of age at the time of recruitment
- Were unable to give consent
- Had significant cognitive impairment
- Were not residing in their own home

The Abbreviated Mental Test briefly assesses cognitive ability. Individuals are asked 10 questions in total. Four of the questions assess orientation to person, time and place. Four questions assess short and long term memory. The remaining questions require individuals to count backwards from twenty and to recognise two familiar people. A score of less than 6 is suggestive of impaired cognition at the time of testing.<sup>209</sup> During this study the researcher only carried out the Abbreviated Mental Test with eligible participants if they suspected significant cognitive impairment.

Individuals with aphasia were included if they could provide informed consent. Where surveys were completed face-to-face researchers with a clinical background in stroke care facilitated communication by using simplified language and closed questions as necessary. If a participant wished to respond using gestures or drawings the researcher interpreted the meaning and confirmed the answer with the participant. Researchers allowed sufficient time for all participants to understand each question and to respond effectively.

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<sup>209</sup> Hodkinson, 1972

## Research tools

A questionnaire was developed to assess respondents' own perceptions of their recovery and community integration. This dealt with changes in everyday activities and experiences since the onset of their stroke. The questionnaire was developed from existing validated questionnaires with the permission of the original authors. Most of the questions and the general format of the questionnaire were based on the UK Stroke Survivor Needs Survey.<sup>210</sup> Some questions from the Daily Life Survey also from the UK were included.<sup>211</sup> Questions were adapted where necessary for the Irish setting.

Members of a community stroke support group piloted and reviewed a preliminary version of the questionnaire. Changes were made to the questionnaire based on the group's feedback in June 2013. Many questions based on five-point rating scales were collapsed into three choices for simplicity. The number and complexity of questions was reduced. Questions about additional common problems experienced including swallowing difficulties and writing difficulties were added. Boxes were included after key questions to give participants the option of including further details. A positive open-ended question was added to the end of the survey to capture primary self-reported factors that have helped stroke survivors' recovery.

There were 49 closed questions in the final questionnaire. Sixteen of these questions included boxes to capture further detail. The questions covered the following domains:

- Information about stroke
- Health after stroke
- Everyday living
- Work and leisure
- Family, friends and use of support groups
- Personal and household finances

An open-ended question asked respondents to identify any other needs experienced since the stroke that had not been dealt with earlier in the questionnaire. A second open-ended question asked a positive question about

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<sup>210</sup> McKevitt, et al., 2010

<sup>211</sup> The Stroke Association, 2012

what had helped participants' recovery most since returning home after their stroke.

Demographic information was captured at the end of the questionnaire. This included age, gender and time since first and subsequent strokes. Marital and residential status was also recorded. Location was categorised as Dublin, Other Urban or Rural. The complete survey instrument can be seen in Appendix 3.

## **Fieldwork**

The researchers (MW, FH and RG) made initial contact with the stroke group coordinators and explained the study to them. Coordinators then identified eligible members within their groups and informed them about the study. The researcher arranged to visit stroke support group meetings at the convenience of members. Eligible volunteers were given the option of completing the survey face-to-face with a researcher, completing the survey independently and returning it by post or completing the survey online. Pre-paid addressed envelopes were provided to participants wishing to avail of the postal option. The purpose of the study and the procedure was explained fully to all potential participants. They were provided with an information leaflet and the researcher's contact details. They were encouraged to ask questions to clarify points that remained unclear. Researchers asked participants to sign a form volunteering informed consent if they were happy that they understood the study procedure and wished to continue. Participants were also made aware that they could withdraw from the study at any time, without giving a reason.

Online responses were recorded using the Survey Monkey application. The link to the online survey was available with the advertisements on the Irish Heart Foundation Stroke website, the Headway Ireland website and both organisations' social media. A full explanation of the study was detailed on the introduction webpage of the survey. Potential risks and benefits were detailed as well as contact details of the researchers. Participants were required to provide consent before proceeding with the online survey. A large "Withdraw From Study" option was available throughout the study in the top right hand corner of each page. Participants were given the option of providing contact details for the sole purpose of receiving a copy of the final report. IP addresses were not recorded to protect participants' anonymity.

Ethical approval was sought and granted for this study by the Royal College of Surgeons in Ireland, Research Ethics Committee. Some jurisdictions required local ethical approval to be obtained before contacting potential participants. Therefore, ethical approval was also received from Naas General Hospital Research Ethics Committee. Approval was sought from HSE Midlands Area Regional Ethics Committee, however time constraints did not allow us to access participants in this area.

## **Appendix 3: National Survey Instrument**

Please see accompanying PDF "Appendix 3\_NationalSurveyInstrument.pdf"





## Appendix 4: Glossary of Technical Terms

Term	Definition
95% Confidence level	The range of values within which we can be 95% sure that the true value lies for the whole population of patients from whom the study patients were selected. <sup>212</sup>
A priori	Statistical analyses specified in the trial protocol; that is, planned in advance of data collection. In contrast to unplanned analyses. <sup>213</sup>
Abstract	A brief summary of the study and its results. It should tell you what the study tried to show, how the researchers went about it, and what they found. <sup>213</sup>
Aphasia	A problem with communication because of damage to an area of the brain. A person with aphasia may find it hard to talk, read, write or understand others when they speak. <sup>214</sup>
Categorical data	Data that are classified into two or more non-overlapping categories. <sup>213</sup>
Chi-squared Test	The Chi-squared test of association allows the comparison of two attributes in a sample of data to determine if there is any relationship between them. <sup>215</sup>
Constant comparative method	A form of qualitative content analysis where each category is searched for in the entire data set and all instances are compared until no new categories can be identified. <sup>216</sup>
Continuous data	Data with a potentially infinite number of possible values within a given range. <sup>213</sup>
Credibility	The quality or trustworthiness of a piece of qualitative research. It can refer specifically to the extent to which the findings and explanations within a qualitative report are recognised and understood by the participants, but can also be extended to include considerations of all aspects of the study. <sup>216</sup>
Data saturation	The point at which no further themes are generated when data from more participants are included in the analysis. The sampling process can be considered to be complete at this point. <sup>216</sup>
Dysarthria	A condition in which speech is slowed, slurred or distorted due to muscular problems caused by damage to the brain or nervous system. <sup>214</sup>
Framework analysis	A method of qualitative data analysis involving five key stages: familiarisation, identifying a thematic framework, indexing, charting, and mapping and interpretation. <sup>216</sup>
Grounded theory	A qualitative research methodology with systematic guides for the collection and analysis of data, that aims to generate a theory that is 'grounded in' or formed from the data and is based on inductive reasoning. This contrasts with other approaches that stop at the point of describing the participants' experiences. <sup>216</sup>

<sup>212</sup> Buckingham et al., 2008

<sup>213</sup> Cochrane Collaboration

<sup>214</sup> National Stroke Foundation

<sup>215</sup> Easton and McColl, 1997

<sup>216</sup> King's College London

Hemianopia	A loss of vision to one part of the visual field. This can lead to trouble seeing on one side of your body. <sup>217</sup>
Incidence	The number of new occurrences of something in a population over a particular period of time. <sup>221</sup>
Interquartile range	The range of values that contains the middle 50% of the sample. <sup>220</sup>
Mann Whitney-U	A statistical test used in place of the two-sample t-test when the normality assumption is questionable. It tests whether two distribution functions differ only with respect to their median. <sup>220</sup>
Mean	An average value, calculated by adding all the observations and dividing by the number of observations. <sup>221</sup>
Median	The value of the observation that comes half way when the observations are ranked in order. <sup>221</sup>
Mixed methodology research	Integrating quantitative and qualitative research methods in one study. <sup>218</sup>
Naturalistic methodology	Qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them. <sup>219</sup>
Non-parametric tests	Statistical tests often used when certain assumptions about the underlying population (e.g normal distribution) are questionable. <sup>220</sup>
Normally distributed	Data are symmetrically distributed about a mean value, and the shape of the distribution can be described using the mean and standard deviation. <sup>221</sup>
P-Value	The probability (ranging from zero to one) that the results observed in a study could have occurred by chance. <sup>221</sup>
Phenomenology	An approach that allows the meaning of having experienced the phenomenon under investigation to be described, as opposed to a description of what the experience was. This approach allows the reader to have a better understanding of what it was like to have experienced a particular phenomenon. <sup>222</sup>
Qualitative research	Research that derives data from observation, interviews, or verbal interactions and focuses on the meanings and interpretations of the participants. <sup>223</sup>
Quantitative research	Explaining phenomena by collecting numerical data that are analysed using mathematically based methods (in particular statistics). <sup>224</sup>
Randomised controlled trials	An experiment in which two or more interventions, possibly including a control intervention or no intervention, are compared by being randomly allocated to participants. <sup>221</sup>

<sup>217</sup> National Stroke Foundation

<sup>218</sup> Guest et al, 2012

<sup>219</sup> Denzin and Lincoln, 2005

<sup>220</sup> Easton and McColl, 1997

<sup>221</sup> Cochrane Collaboration

<sup>222</sup> King's College London, 2013

<sup>223</sup> Holloway and Wheeler, 1995

<sup>224</sup> Aliaga and Gunderson, 2003

Randomised Stratified sample	A stratified sample is obtained by taking samples from each stratum or sub-group of a population. <sup>225</sup>
IBM SPSS Statistics	A computer software package for completing statistical analysis
Standard deviation	A measure of the spread or dispersion of a set of observations, calculated as the average difference from the mean value in the sample. <sup>226</sup>
Systematic review	A review of a clearly formulated question that uses systematic and explicit methods to identify, select, and critically appraise relevant research, and to collect and analyse data from the studies that are included in the review. <sup>226</sup>
T-test	A statistical test used to compare continuous data in two groups. <sup>226</sup>
Thematic analysis	Concepts (explanatory ideas) are identified from the data in the first stages of analysis and given a label or code that describes them. Concepts which are closely linked in meaning can be formed into categories: categories which have similar meanings can be brought together into a theme. <sup>227</sup>
Triangulation	A process by which the area under investigation is looked at from different (two or more) perspectives. These can include two or more methods, sample groups or investigators. Used to ensure that the understanding of an area is as complete as possible or to confirm interpretation through the comparison of different data sources. <sup>227</sup>

<sup>225</sup> Easton and McColl, 1997

<sup>226</sup> Cochrane Collaboration

<sup>227</sup> King's College London, 2013

